

## LETTER OF INFORMATION

### CEREBRAL PALSY RESEARCH

n° 2 Autumn 2007

## The Fondation Motrice

Join us to say that research is  
essential!



The Board of the Fondation Motrice during  
a visit by its patron, A. Casiraghi, and its team  
(Photo Vincent Lepreux)

Dear friends,

This latest newsletter reflects the aims of the foundation:

- The Fondation Motrice is a crossroads (see p. 2-4). We give voice to a member of the scientific council, to a research grant beneficiary and to a person with CP to speak about epidemiology: what we expect from it, and that which it can bring. Each person gives their qualified opinion.
- The Fondation Motrice has become a pole of attraction for researchers: we have received 57 research projects - a quarter of these from abroad - in response to our 2007 research call. The selection was based on the quality of the projects and their interest for the foundation. (see p. 5).
- We wish to construct a shared vision of priorities for the future. An important future study will be launched during the next scientific council (see p. 4).
- The strength of the foundation must be rooted in a large support network. Michèle Baron, president of the French Federation of CP Associations is interviewed on p.6. The support that she brings to the foundation, as the representative of all of the associations who care for children and adults with CP, is of great importance to us. Our forces are not only added to, they are multiplied.

The first endeavours undertaken by the Friends of the Fondation Motrice and by our patron for the benefit of research have been a great success (see p. 6). Many thanks to them!

The development of the Friends of the Fondation Motrice network is a key issue for us. Cerebral Palsy affects 125,000 families in France and 650,000 in Europe. What an impact it could have if 1 in 10 were to commit to membership or enlist others to become members! What capacity to react in favour of research.

**Join us to say that research is essential !** Join the Association of the Friends of the Fondation Motrice, put up posters for the Fondation Motrice, propose projects to us for the benefit of research....

We have been spurred on by the expectations of the young with Cerebral Palsy, those whom we know, or those whom this project has given us the opportunity to meet. Their hope is a tremendous responsibility which we carry with us through our actions.

**Science is an issue of resources: get involved with us, we will find them together!**

Alain Chatelin,  
Chairman of the board

## THE FONDATION MOTRICE

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2006

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## Dossier

# EPIDEMIOLOGY STUDIES (1)

Epidemiology studies are a key element in the understanding of Cerebral Palsy, and the Fondation Motrice supports several projects in this domain.

Doctor Christine Cans, member of the Scientific Council of the Fondation Motrice, explains this little-known discipline.



### What is epidemiology and what does an epidemiology study consist of?

Epidemiology is the study of the characteristics, the modes of transmission, the causes or the risk factors of illnesses. An epidemiology study consists of studying one or other of the aspects in a certain group: in the general population or in a particular sub-section of the population.

Clinical epidemiology designates the concepts and methods of the epidemiology used to test hypotheses related to a diagnosis or prognosis and the treatment of pathologies or clinical situations.

### What is the purpose of epidemiology studies, what do they teach us?

Epidemiology studies of which there are 2 kinds, can serve different objectives.

- descriptive studies :

- some aim to quantify the extent of a phenomenon, for example to measure the frequency (incidence or prevalence<sup>1</sup>) of an illness
- others aim to measure the impact of means used to modify the frequency of an illness
- finally, the “cohort studies” for example, allow us to follow the developments of a subset of the population (the cohort) identified as being at risk, or not, of developing certain illnesses.

- analytical studies :

- Their objective is the prevention of an illness or the improvement in the level of understanding by an analysis of the mechanisms causing this illness. More often, they try to identify the factors of risk of an illness, and to locate among them the most important factors to which it can be attributed. This can lead to the objective of prediction: knowing that an individual presents a certain risk factor, what is the probability that they will become ill?

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<sup>1</sup> **the incidence** corresponds to the number of new cases annually: each year, 1800 newborns are affected by Cerebral Palsy in France, around 10 000 in Europe  
**the prevalence** is the total number of cases existing in a population : there are 100,000 to 150 000 people with Cerebral Palsy in France, over 650 000 in Europe

### What can we expect?

In the domain of Cerebral Palsy or childrens' disabilities :

- a better description of the characteristics of the affected children, and their evolution over time : is the number in decrease? Are the cases now more severe than previously? What are the consequences of the pathology in terms of quality of life? What are the factors that can influence the outlook of the people affected?
- An improvement in the understanding of the principal risk factors, and of the factors for which preventative measures are easily envisaged: does a preventative treatment exist for the risk factor? Which sub-section of the population most needs to be monitored?

### What do these studies change in real terms for disabled people?

Epidemiology studies are important for several reasons. They serve to:

- Bring the large numbers of people affected to the attention of the public authorities.
- inform politicians about the consequences in terms of quality-of-life and on the impact of the environment in such a way as to recommend changes.
- propose preventative measures
- inform the healthcare professionals involved about the factors to take into consideration and the co-existence of associated deficiencies.
- For the disabled people themselves, the contribution is indirect: the augmentation of understanding of the characteristics of their pathology will lead to better levels of care for them.

### How epidemiologists work:

- collect the data
- describe it
- compare it
- research the associations
- confirm the associations observed
- research the causality (relationship between cause and effect)
- evaluate the health aspect
- evaluate the health actions

# EPIDEMIOLOGY STUDIES (2)

**Mélanie White-Koning,**

**statistician and beneficiary of a grant from the Fondation Motrice which helped to support her thesis on epidemiology, explains her work on the quality of life of children with Cerebral Palsy in Europe.**



## **What are the measures for the quality of life?**

The evaluation of quality of life is presented in the form of questionnaires which allow for a quantitative and reliable translation of the subjective reality of the individual's feelings.

The interest of these measurements is to not limit the approach to the illness to just the doctor's perception, but to also allow the patient to express their own point of view.

For the study of the quality of life of the child, we restricted ourselves for a long time, to only questioning the parents, believing that the children themselves weren't capable of giving reliable responses. This notion has been widely discredited, as numerous studies have proved the reliability of their answers. My work involving children with CP in Europe has confirmed the importance of interviewing, as far as possible, both the children and their parents. The divergences in their responses are considered rather as complementary points of view instead of a lack of reliability.

## **Have advances in this domain been implemented? If so which?**

We can already consider as important progress the fact that attention is being directly placed on the point of view of the children. The European study SPARCLE on which I am working has shown that the population of children with CP capable of responding themselves had an average level of quality of life comparable to that of children in the general population. The approach of the children with more severe difficulties which I could glean from the responses of parents and professionals, shows that outside of the physical domain, these children are not overall different from those who have less severe forms of CP. Within each of these groups, the study of factors associated with a lesser quality of life has allowed for the identification of the areas which need to be improved : it concerns the suffering of the children and the stress of the parents.

## **What will your studies change in concrete terms for people with disabilities?**

On an individual level, the families who participated in these surveys have expressed their satisfaction with being the subjects of this interest. This study, financed by the European Union, also contributes to different detailed reports about the situation in each country. We can therefore hope that European, national and local politics will be influenced by the findings.

Furthermore, the publication of the results in international scientific journals is the opportunity to focus the attention of pediatricians on the different problems studied, and can contribute to broadening their field of interest beyond strictly the domain of pathology. The results, outlined

above, concerning the link between the quality of life of the child on the one hand, and parental stress and suffering of the child on the other, should lead to an improvement in practices and give rise to new research.

Quality of life:
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- |   |
|---|
| <ul style="list-style-type: none"><li>• Quality of life is the perception that an individual has of his life in the cultural context in which he lives and in connection with his values, his objectives and his ambitions.</li></ul> |
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Definition from OMS – 1993)
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Quality of life comprises:
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- |   |
|---|
| <ul style="list-style-type: none"><li>• Material conditions</li><li>• The physical status and functional capabilities</li><li>• Social interaction and emotional and psychological well-being</li></ul> |
|---|

# EPIDEMIOLOGY STUDIES (3)

## Point of view

**Richard Fernandez occupies a special place in the Fondation Motrice: having CP himself, he is the director of a centre for people with CP in Brittany, and an administrator of the Fondation Motrice since its creation. The following are his views on the interests of improving quality of life and on research in general**



What would you wish to learn from the analysis taken to improve the quality of life of children and adults with CP, how useful are they in improving the support of people with CP?

We are awaiting, above all, the criteria for the evaluation of “quality of life” and the emergence of a system of reference which currently does not exist. This would allow for an objective view and free us from subjectivity. We will have a tool to help discussion and decision making.

Up to now, we can see disparities between that which the professionals and families believe to be good, and that which the disabled person really wants : there is a tendency to want to put oneself in the place of the dependent individual, but it is more complicated than that. For example, we may decide to take someone out of an institution and install them in an apartment because it seems like a good solution for them, and eventually we realize that the consequences are less satisfactory than we would have expected.

These studies must therefore help us to establish another model for quality of life than the given “normal” model which is “to be autonomous, get married, have children, a job, a house and a car”. People with CP, not having any alternative for the moment, want to adhere to this model as closely as possible, but end up feeling cheated. It is very revealing to note that, as opposed to the small child with CP who is very dynamic and always wants to move forward, adolescents and adults with CP can have terrible bouts of depression : through growing, they are confronted by the short-comings in their social rapports, their attempts to find work etc. Therefore, thanks to these studies we will be able to deepen the analysis, we will be able to objectify and try to define the “CP-way-of-life”, as part of society, and within society, whilst remaining different.

### **What do you hope for, on a broader scale, from the Fondation Motrice?**

There are two principal motivations behind my involvement with the Fondation Motrice since its inception:

- \*Firstly, it is imperative to encourage theoretical and medical research to improve understanding of this pathology and the implied consequences for brain injuries ;

- \*However, applied research must also be encouraged in order to improve quality of life. For example the development of software to compensate for speech difficulties ; greater understanding of learning at school; all things pertaining to the psychological aspects of CP (for those with difficulties and their families) and also dealing with the aging process. We must make progress in all of these domains.



## Focus

### European Research Networks

In order to improve the collaboration between researchers and encourage the efforts of CP research, networks have been set up. Among them SCPE (the European surveillance of CP network) gathers epidemiologists, neonatologists, obstetricians, neuropsychiatrists and geneticists under the co-ordination of Dr. Christine Cans. The first mission of this network has been to arrive at a definition and a common classification of Cerebral Palsy, and to create a database on the pathology. Today, its role consists of enriching this database and in stimulating the studies on the subject of Cerebral Palsy.

### The EBLES\* project

Training of young researchers and doctors in Cerebral Palsy research. Co-ordinated by Prof. Ingeborg Krägeloh-Mann, member of the Scientific Council of the Fondation Motrice, this project regroups 8 European teams, each one responsible for receiving post-doctorate or thesis researchers for training in the different disciplines pertaining to the research of Cerebral Palsy in order to give them a global vision. This project has been submitted to the EEC for financing.



\* *Early Brain LESions*

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### Fondation Motrice News

.....to follow in the next newsletters.....

#### **“New rules and new opportunities in the development of medications for neuropsychiatric disorders: the cerebral palsy example”**

Breakfast conference organized with Dr. Pierre Gressens and Pr. Gérard Pons last June 22<sup>nd</sup> by the Fondation Motrice in partnership with the French association of pharmaceutical physicians (AMIPS).

#### **Future study for the research of Cerebral Palsy. A Fondation Motrice project selected by the French National trust for autonomy (CNSA).**

The CNSA (French national trust for autonomy of disabled or elderly people) has awarded €120,000 to the Fondation Motrice for the execution of a future study whereby the objective is to determine the needs and expectations in research terms, and also the feasibility and possible timelines for achieving significant progress in the domain of Cerebral Palsy. With this objective, this study will bring together people with CP and their families, healthcare professionals and caregivers, as well as concerned associations and administrations in order to define their expectations and elaborate with



the researchers, a vision of the progressive steps possible and their potential time frames.

To construct this shared vision of the future will contribute towards defining the directions for the foundation to take. It will also be an important communication resource in helping to understand this domain.

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## THE LAUREATES

### 2007 Research call

**The research call launched in March 2007 by the Fondation Motrice received 57 candidatures worldwide, of which 10 have been selected by the Scientific Council of the Fondation Motrice on June 25<sup>th</sup> 2007, for a total amount of €257,500.**

**The following is an overview with Lucie Hertz-Pannier, member of the board, on the directions which will be undertaken.**

The Scientific Council of the Fondation Motrice is committed to selecting the projects based on the criteria of scientific excellence, innovation, and relevance with regards to the prevention and / or the improvement of the quality of care of CP. We can divide the chosen projects into 3 spheres.

**1 Prevent** CP by means of an accurate comprehension of the mechanisms of its predisposed cerebral lesions, often thanks to animal studies which allow for the testing of new treatment methods before being tested on humans.

- M. Delcour : development of a CP animal model and of strategies of functional rehabilitation.
- P. Clarke : study of the death of neurons in a model of cerebral injury in newborn rats.
- E. Goux : study of the dysfunction of glial cells (which surround the neurons) and of the related neuronal death in models of perinatal cerebral injury.
- O. Touzani : The use of MRI and of behavioural tests in animals to evaluate the effectiveness of a new treatment in cerebral injuries of newborn animals.

**2 Better comprehend and describe the physical and cognitive disorders** existing in patients with CP, as well as their consequences on quality of life, in order to deal with them more effectively.

- V. Achache : study of the underlying mechanisms in the physical disorders of patients with cerebral palsy.
- S. Bensamoun : non-invasive study of the muscular elasticity in the patient with CP through a new method (elastography by magnetic resonance imaging or MRI).
- M. Molina : mental representation of movement and simulation of gesture in the child with CP
- K. Lidzba : study of the organization of language by magnetoencephalography in children with CP related hemiplegia.
- S. Chabrier : evaluation – among 3 and 5 year olds - of quality of life, level of autonomy and motor function globally - in 100 children having had a neonatal cerebrovascular accident.

- C. Arnaud : social support and quality of life of adolescents with CP, study of children from the Haute-Garonne region of France.

### **3 Reduce the effects of cerebral lesions.**

- N. Bahi-Buisson : study of the effectiveness of a new medication (tetrabenazine) for the treatment of abnormal movements among children with CP.

**The globality of these undertakings feeds the hope of one day being better equipped to prevent the occurrence of new cases of CP, and the improved treatment and care of its existing subjects.**

## **Our support and benefactors**

### **4 Questions for....**

**.....Michèle Baron, President of the FFAIMC**

The French Federation of CP Associations brings together the parents' associations which it unites around the founding principal : "the person with Cerebral Palsy comes first".

#### **Why do we still need to support research into CP?**

This research has many gaps : since the work of Pr. Tardieu in the 1960's, researchers have turned away from this difficult and little publicized subject. Other types of research into the brain (Alzheimer's, Parkinson's etc.) are today at the forefront, and CP research has not been included in this. Therefore, it is fundamental that this abandoned research is started up again. This is why we are placing such importance on the creation of the Fondation Motrice.

#### **What are the associations that you represent expecting from the Fondation Motrice?**

We are expecting two things:

-Firstly, fundamental research: how can we lower the rate of incidence of CP?

-Secondly and equally important, applied research: how can we improve the daily life of the person with CP and alleviate their difficulties? We do need short term results: what can the research do to improve the lives of those already here?

#### **How can you help with the research from your side?**

As active stakeholder we wish to promote the actions of the Fondation Motrice and help to get its word heard by the public authorities: we want to make our weight and presence felt by the authorities!

#### **What is the message for the general public?**

We must make CP known to the public so that they can realize that this accident can happen to anyone. Maybe we should organize an event on a national level, like the Téléthon for example. We also need to mobilize the media in order to raise the necessary funds. I would like to think of the research in these terms: even if I cannot see it when I look to the horizon, I know that the sun is there and that it will pierce it. Thanks to this research, we want the sun to rise for our children.

## Benefit dinner at Maxim's in Paris.

**More than €60,000 collected in aid of Cerebral Palsy research.**



The first gala dinner to benefit the Fondation Motrice was held last June 20 2007 in Maxim's, organized by the patron of the foundation Andrea Casiraghi, his friends, and the Maxim's team with the help of the Fondation Motrice.

The amount collected comes from, among other things :

- the proceeds from the table reservations by HRH the Princess of Hanover, M. Carnot, Armani, Chanel, Gucci, Nestlé, the magazine Point de Vue, Prada, Repossi, the Thaddeus Ropac gallery and Versace
- the auction proceeds of prestigious lots offered by the designers
- the entrance fees to the after dinner soirée.

This soirée was equally the subject of particular press attention notably in publications of large readership like Point de Vue, Paris Match (France), Bunte (Germany), and Women's Wear Daily (USA), thereby helping us to bring the cause of CP research to a wider audience.

## An initiative by a Friend of the Foundation

The Annual lottery of the Soroptimist club of Uzès raised €5,000 for the Fondation Motrice.

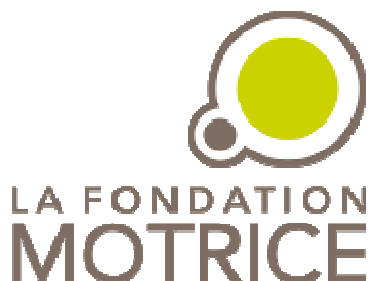
Thanks to the undertaking of Joëlle Margarita, member of the club and mother of a child with CP who is a resident at PasseR'aile, the annual lottery, traditionally dedicated to a cause or an association, was organized this year for the benefit of the Fondation Motrice. The exceptional collection of €5,000 has been transferred in its entirety towards cerebral palsy research. We would like to warmly thank the participants for their generosity and the members of the Soroptimist club for their support.

**You too !**

**Join the Friends of the Fondation Motrice !**

**The goal of the association of the Friends of the Foundation is to support the foundation and to supply it with the means in short, medium or long terms to carry out its research. Its members\* are individuals or entities who can bring their expertise, their time towards fund-raising, a financial contribution or access to their network. Created at the same time as the Fondation Motrice, the association of the Friends of the Fondation today needs to expand its network of members to all regions. This network will be responsible for organizing events and projects for the benefit of the Fondation Motrice throughout France, in collaboration with all of the associations who wish, to support the action of the Fondation Motrice in aid of research. Contact the Friends of the Fondation : [info@lafondationmotrice.org](mailto:info@lafondationmotrice.org)**

\* **To become a member**, the annual fee of €40 is in the form of a donation towards research (see bulletin form underneath)



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**I wish to donate the sum of :**

☐ € 40      ☐ € 60      ☐ € 100      ☐ € 150      other : ..... €

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If you wish to make your donation by monthly standing order, please contact us.

La Fondation Motrice is recognised as a government approved charity ("*Fondation reconnue d'utilité publique*"): with respect to French legislation your donation gives you the right to an income tax reduction of 66% of the amount of your donation. Thus, a €100 donation will cost you €34 if you are liable for tax.

If you are paying taxes outside France consider local legislation.

**At the occasion of this donation, I wish to become a member of the Friends of the Fondation Motrice**

☐ **yes**

☐ **no**