

**Together for the research on  
Cerebral Palsy !**



*“ Nous  
avons besoin  
de vous ! ”*

*“We need  
your help!”*

[www.lafondationmotrice.org](http://www.lafondationmotrice.org)

These research projects have seen the light of day thanks to La Fondation Motrice. Progress is possible on condition that we maintain our efforts. For this, we need your donations and your support.

## MOLECULES IMPLICATED IN CEREBRAL LESIONS: RESEARCH OF THERAPEUTIC TARGETS FOR NEUROPROTECTION

**Dr. P. GRESSENS** – U676 Pathophysiology and neuroprotection of the affected developing brain - **INSERM Robert Debré Hospital, Paris (France)**

Our laboratory works generally on brain illnesses in children with the objective of finding new treatments. The most important are those which occur at birth, most notably those which concern premature births and for which there is no treatment as yet: these illnesses leave lasting consequences, affecting motor skills, intelligence or speech. We are thus trying to **understand the problems which affect the brain** in order to be able to treat, and one day repair, them.

One of our specific projects consists of the development of models in animals presenting lesions comparable to those of the premature newborn child. We are trying to determine which are the cells and molecules that play an important role in these lesions in order to target the mechanisms which would block the process of the formation of the lesions. For some of these molecules, the projects are long-term. But we are equally studying molecules present in existing medications (such as antibiotics) which could play a role in protecting the brain. At present, we are in the process of validating results in large animals before passing on to humans.

Another axis of research is, no longer to prevent, but to treat the lesions when it is too late to block their appearance: the question is to find out if the missing brain cells can be replaced. For one year, we have been working on the subject of cellular therapy, including stem cells, in order to be capable of one day repairing cerebral lesions in the newborn. For this project, the estimated time frame is between 5 and 10 years.

**Our laboratory benefits from the support of La Fondation Motrice since its creation, which permits us, almost every year, to employ a person full-time (generally a researcher working on a thesis) in this area.**

**Prevent and protect**

**19 projects  
financed  
in this category  
since 2005**



**« Research is important so that there will be fewer like me »  
Caroline**

**« The training of professionals should take the progress being made in research into account »  
Claudine, her mother)**



## Understanding the disorders

17 projects financed in this category since 2005

## THE NETWORKS OF NEURONS IMPLICATED IN THE TREATMENT OF LANGUAGE IN CHILD AND ADOLESCENT HEMIPLEGICS.

**Karen LIDZBA – Department of Pediatric Neurology and Developmental Medicine – University of Tübingen (Germany)**

Our project is to study the organization of language in children and adolescents who have suffered damage to the left hemisphere of the brain where the linguistic faculties are normally concentrated. By using a completely new method of brain exploration (magneto-encephalography), we are able to study in real time the topography and the dynamics of nerve cell networks related to speech, in order to understand the pathology and how the reorganization of linguistic faculties in the other hemisphere compensates.

**The support of La Fondation Motrice allowed for the financing of a PhD researcher on the subject in 2007.**

## PERCEPTION OF SPACE AND INTEGRATION OF PERCEPTIONS FOR MOVEMENT

**Dr. V. BELMONTI – IRCCS Stella Maris and Department of Developmental Neuroscience, University of Pisa (Pr. G. Cioni) (Italy) – in partnership with the Laboratory of the Physiology of Perception, Collège de France (Pr. A. Berthoz).**

The objective of our study is to understand the strategies of the perception of space during movement in children, in order to envisage new therapeutic approaches. The study includes the analysis of the processes of perception of space during real movement (movement towards a target, ability to grasp an object) and analysis, by new methods of brain imaging, of the neuron networks which permit spatial orientation.

**The support of La Fondation Motrice will allow for the development of this innovative approach, and the facilitation of cross-border cooperation between two teams of the highest level in France and Italy.**

**“Too often, we confuse the problems of elocution and intellectual deficiencies :**

**I would like to be more respected and that people would listen to me” Orlane**



## IMPROVING THE REPAIR OF CEREBRAL LESIONS / THE EFFECTS OF INTERACTION WITH THE ENVIRONMENT

**Ann LOHOF, Rachel SHERRARD – U 712 Neurobiology of adaptive processes – University Pierre and Marie Curie, Paris VI (Pr. Mariani) (France)**

The purpose of our study is to show in animals, whether by stimulating interaction with the environment, and thereby stimulating sensory activity, one can encourage the repair of the brain and the formation of new functional

**Act on the disorders and their consequences**

**9 projects financed in this category**

**connections**, allowing for an improvement in motricity and learning skills.

since 2005

**La Fondation Motrice will finance temporary positions for researchers in this unit.**



“Can we cure Cerebral Palsy one day?”

## EVALUATION OF THE QUALITY OF LIFE AND THE AUTONOMY OF CHILDREN WHO HAVE SUFFERED A CEREBROVASCULAR ACCIDENT AT BIRTH .

**Pr S. CHABRIER, Paediatric Service, CHU Saint-Etienne (France)**

The principal objective of our study is to establish the profile during pregnancy and around the birth of newborn infants having suffered a cerebrovascular accident , and then to determine the mechanisms involved. Determining this « at risk » profile will be important in prevention, surveillance and early treatment. Defining early prognostic factors will **permit the family to be better informed and also to prepare the necessary health care**. The evaluation of autonomy, quality of life, and motor function will furthermore allow for a better focus on the best types of treatment in the interest of and for the well-being of the child, taking into account the socio-psychological aspect for the family, thus favouring adherence to the therapeutic project.

**Since 2006 La Fondation Motrice has been the principal support in enabling the continuation of this study. Without this funding, the monitoring of children would have ended before the minimal objective of 5 years was reached.**

**Improve the quality of life**

## SOCIAL SUPPORT AND QUALITY OF LIFE OF ADOLESCENTS WITH CEREBRAL PALSY ;

**Catherine ARNAUD, U558 INSERM Université Paul Sabatier, Toulouse (France)**

The objective of our study is to evaluate young peoples' perceptions of their social support networks (notably the family, siblings, friends...), as a factor in improving their quality of life. The measurement of the impact of familial support as a factor associated with well-being, independently of the severity of the disability will be a very useful element in the guidance and care of adolescents with Cerebral Palsy.

**La Fondation Motrice has sponsored part of the cost of this project.**



**« We must have the technical means and social innovations which will give us our independence »  
Frédéric**



**« For me, it is vital to improve the Tools which aid communication »  
Meir**

## **STUDY OF INTERFACES FOR INDICATING AS TECHNOLOGICAL AIDS**

**Eric MONACELLI, Head lecturer – Laboratory of Systems Engineering, University of Versailles-San Quentin en Yvelines (Y. Alayli, Director) – in partnership with the National Hospital of Saint Maurice (Dr. Quentin, chief of service) (France)**

Access to computer skills today allows people with Cerebral Palsy to develop their autonomy for communication, recreational purposes or work. Access to a computer for the most severely affected persons is only possible as a result of specialised interfaces (tools which play the role of the mouse), and which are chosen specifically in relation to the disabilities of the user. The aim of our work is to develop a free software tool which would aid each therapist and each disabled person in selecting the most suitable system for their individual needs, and to define the specific parameters (sound effects, visuals, or touch sensitive) to allow for more efficiency.

**This project will have financing from La Fondation Motrice.**

## Projects rigorously selected, and which respond to the needs of people with Cerebral Palsy and their families.

The projects we support have been carefully chosen by the Scientific Council of La Fondation Motrice within the Framework of the appeal for projects we launch each year. Dr. Lucie Hertz-Pannier, General Secretary of the Foundation explains the principles.

« The principle of appeal for projects is common practice because a large part of the research in France is financed in this manner, by associations or foundations. Our singularity is to be practically the only one which finances research projects specifically related to Cerebral Palsy.



Every year, the Scientific Council retains one or more research themes, chosen according to the priorities determined by the Fondation. Since 2005, we have received 171 candidatures and retained 45 projects.

Each project received is evaluated by a member of the Scientific Council and another external expert, according to a grid and strict criteria. All of the projects are then ranked according to the notes obtained and the priorities of La Fondation, and, as a result of this collective reflection, the Scientific Council proposes a list of candidates to the Administrative Council which decides on the distribution of research grants. For all of the projects we keep, we then establish the agreements between the laboratories or universities involved. The progress of each financed project is controlled and will be subject to publication in a scientific revue.

### Priority areas of research



In order to best determine the needs and expectations in terms of research materials on Cerebral Palsy, as well as the feasibility and deadlines for significant progress, La Fondation Motrice, in 2008 launched a prospective study, supported by the CNSA. The results will allow us to identify the most important fields of research for future appeals for projects.



**A workshop of shared discussion.)**

*Service of Cognitics, Robotics and Interaction  
(R. Gelin) of CEA .*

**Since 2005, La Fondation Motrice has supported 45 research initiatives and established partnerships with recognized universities and laboratories.**

**Universities and Hospitals**  
**INSERM (France)**  
**CNRS (France)**  
**University of Lausanne (Switzerland)**  
**University of Maryland (USA)**  
**University of Pisa (Italy)**  
**University of Tübingen (Germany)**

**There is still much to be done. Help us to prevent Cerebral Palsy and to improve the lives of those who are affected by it.**





## Why donate to La Fondation Motrice ?

“Cerebral palsy is the first cause of motor handicap in children. We are all concerned as any child can be a victim. For all our children and young people, La Fondation Motrice is a symbol of hope and a testimony of our interest in their future. La Fondation has become a valued actor in the research sector and has launched numerous projects in a very short time. We have asked well know experts to select these projects and put in place a prospective approach to involve handicapped people in determining the priorities. However, in 2007, we have been able to allocate only the equivalent of €2 per handicapped person to subsidise research projects (grants, part time work and equipment).

There are 125 000 persons suffering from cerebral palsy in France, 125 000 families directly affected and therefore several hundred thousand people who know personally a child or an adult with this handicap. We could so much more if only 1 out of 10 helped us support research. Will you be one of them?”

Dr. Alain Chatelin  
Chairman  
La Fondation Motrice

It costs € 30 000 to finance one year of research  
for a doctorate thesis.

Cerebral palsy can affect any newborn infant  
and its effects will last all his/her life.

## Tax benefits for donations

### ► Individuals

**Income tax reduction (art.200, French tax code)** You are entitled to a tax reduction of 66 % of your donation, up to 20 % of your taxable income. Thus the real cost of a € 100 donation is only €34.

Your donation to research	Real cost for you
€ 50	€ 17
€ 100	€ 34
€ 150	€ 51
€ 200	€ 68
€ 500	€ 170
€ 1000	€ 340

OR

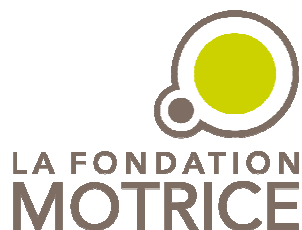
**Wealth tax reduction for donations to a foundation (art. 885-0 bis A, French tax code)**

If you are subject to wealth tax, you are entitled to a tax reduction of 75 % of the amount of your donation. For instance, when donating € 1000 you benefit from a € 750 reduction on the wealth tax. The full amount of your donation goes to La Fondation Motrice and is allocated to research projects and it only costs you € 250. This tax reduction cannot exceed € 50 000;



► **Companies** (*Art. 238 bis, French tax code*)

Companies can benefit from a tax reduction representing 60 % of their donation, up to 5 % of their turnover : a € 1000 donation only cost € 400 to your company.



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**Yes**, I support La Fondation Motrice

First name: ..... Surname: .....

Address: .....

Postal Code: ..... City: .....

Tel: ..... Email: .....

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

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

by cheque payable to "La Fondation Motrice"

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

La Fondation Motrice is recognized as a government approved charity : your donation entitles you to an income tax reduction. Take it into account when you make your donation.

Unless otherwise indicated, by making a donation you will become a Friend of La Fondation Motrice.

## THEY CAME TO HELP US, JOIN THEM !



***“To make a donation to La Fondation Motrice is to give our researchers the means to pursue their work, to finance new research projects to improve the life of those who today suffer from cerebral palsy and to reduce the risk of new cases in the future. Like me, support La Fondation Motrice !”***

**Andrea Casiraghi, Patron of La Fondation Motrice**

Andrea Casiraghi, son of HRH the Princess of Hanover, née Princess Caroline of Monaco, decided to commit himself and support La Fondation Motrice after becoming aware of the difficulties encountered by CP patients through his friend Matthieu, whom he met at university and who has CP.

## THE FRIENDS OF LA FONDATION MOTRICE ASSOCIATION

The purpose of the Friends of La Fondation Motrice association is to develop the support network for La Fondation particularly in relation with fund raising. Today, it has approximately 150 active members. By donating a minimum of € 40, and unless you do not want to, you become a member of the association.

Contact : Marie Perin, Secrétaire Générale  
[mperin@lafondationmotrice.org](mailto:mperin@lafondationmotrice.org)  
[contact@lafondationmotrice.org](mailto:contact@lafondationmotrice.org)

The Friends of La Fondation Motrice organize various operations in support of La Fondation :

Charity dinners

Auctions


Lotteries

Book sales

Participating in sports events



Diner June 2008

	<p><b>For Stéphanie Arnault, “a call from the heart” !</b></p> <p>For quite some time, I had been looking for a cause to support and when one of my close friends, whose daughter has CP, told me about La Fondation Motrice, its action and the hope it created, I felt a real “call from the heart”.</p> <p>I love children and that is why I created a website, <a href="http://www.memoiresdepetitenfant.com">www.memoiresdepetitenfant.com</a> dedicated to them. I decided to donate half the profit from the website to La Fondation Motrice. La Fondation gives me an opportunity to do more and serve a great and beautiful cause for children, as I feel that personal implication and my donations are truly useful.”</p>
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## **La Fondation Motrice is supported by a large network of associations**

### **Founding associations**

APETREIMC

SESEP

CDI

PASSERAILE-APETREIMC

### **Associations that support us and distribute our newsletter:**

FFAIMC, SFERHE

Assoc. Départementale “Les Enfants des Carnutes, Assoc. Départementale des Enfants Mineurs IMC, Assoc. de l’Essonne “Un sourire pour l’espoir”

ADIMC Charente, Côte d’Armor Foyer Ker Spi, Drôme, Finistère, Haute Savoie, Hérault, Ile et Vilaine, Isère, Loire, Maine et Loire, Mayenne, Sarthe, Saône et Loire ARAIMC, ARIMC Champagne Ardennes, Gironde, Ile de France, Rhône Alpes, ARIMOC Pau Béarn.

ASFA, AVEFETH, Foyer Logement “La Chateau”, GIMC, HUDERF, I=MC2, Institut Le Mai, Service de Rééducation Précoce au Luxembourg.

## **Like them, you can help us !**

## CEREBRAL PALSY IS THE FIRST CAUSE OF MOTOR HANDICAP IN CHILDREN

**Cerebral palsy** is linked to brain damage to the developing brain during pregnancy, during childbirth or after birth up to about age three.

International definition published in 2007 :

“Cerebral palsy is a term that encompasses a group of permanent disorders of movement and posture leading to limitations of activity, caused by non-progressive brain damage to the foetus or newborn infant.”

Motor disorders caused by CP are often accompanied by disturbances of sensation, cognition, communication, perception and/or behaviour and/or by a seizure disorder and secondary orthopaedic difficulties.”

This definition covers a large panel of conditions, all of which need coordinated and diversified multidisciplinary to each child and adult potential development. In France, **cerebral palsy** is also used to characterise conditions that allow a normal school cursus, whereas “**multihandicap**” is used when a combination of severe mental deficiency and motor deficiency lead to extremely restricted autonomy.

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### La Fondation Motrice

La Fondation Motrice was created in 2005 under the auspices of three associations (Apetreimc, SESEP and CDI) dealing with cerebral palsy with a view to bring strong support to research concerning this handicap and help in this field.

La Fondation Motrice is recognized as a government approved charity (*Fondation reconnue d'utilité publique*) by a decree of July 4<sup>th</sup>, 2006.

Its objects are :

- Promoting and support research and innovation in all areas likely to help prevent cerebral palsy ; improving the quality of life of people affected by CP.
- Improving the quality of care, promote the development of best practices and knowledge about cerebral palsy.



1800 newborns are affected each year, i.e 1 out of 450.

Premature babies are particularly vulnerable.

125 000 persons in France

650 000 persons in Europe



Alexandre's head must be supported for him to sit up.

## Scientific Council of La Fondation Motrice

Research projects that receive a financial support from La Fondation Motrice are selected by international experts, members of our Scientific Committee:

Pr M. VIDAILHET (Chairman)  
Pr A.-L BENABID  
Dr C. BERARD  
Dr C. CANS  
Pr G. CIONI  
Dr P. GRESSENS  
Pr P. HUPPI  
M. E. JACOTOT  
Pr I. KRAGELOH-MANN  
M. M. LE METAYER  
Pr G. PONS  
Dr B. ZALC



Pr Marie VIDAILHET

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