

JOIN THEM TO HELP LA FONDATION MOTRICE: THE NEEDS ARE IMMENSE!



Thanks to my friend Matthieu, I have been able to see the indispensable work accomplished by La Fondation Motrice teams. I wanted to see for myself the needs of children suffering from cerebral palsy and their courage and to mobilize my friends and my contacts in any place where I can speak for them. I invite all of you who can dedicate some of your time or donate to join us in the adventure of La Fondation Motrice: there is so much to be done! Thank you for your commitment in favour of these children!

Andrea CASIRAGHI, sponsor of La Fondation Motrice.

IF YOU WISH TO HELP US

**please contact
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Myriam, Lucie and their team at the start of the 2011 Heroes Race

Finding a physio, a place in the neighbourhood school, informing the teachers about cerebral palsy, making a choice between a regular or a special needs school: we are often left alone to face the choices that our child's condition require, and we must devote a lot of energy to find solutions. It took me six years before I could set up a complete care environment for Lucie. Today, we still have to answer her questions: "When will my feet be straight? Why do my legs hurt?" That is why we are interested in research on brain treatment but also on pain and on sleep problems that have had such an impact on our life. Studies on screening are also essential as there are more and more very premature babies like our daughter. For all these reasons, I support La Fondation Motrice projects.

Myriam, Lucie's mum.

➔ After I retired, I wanted to give some of my time to other people. Through La Fondation Motrice, I discovered cerebral palsy and I said "yes" to the idea of acting for a noble and useful cause: that today CP affects one newborn out of 450 is unacceptable! As a woman, mother and grandmother, I want to understand, prevent and do something.



is a real challenge but one that is worth taking on!

Mireille Cayreyre

➔ Our daughter Camille will soon be eighteen and suffers from cerebral palsy: our family is therefore affected by this handicap.

Board member of **The Friends of La Fondation Motrice Association**, I launched four years ago **Les Diners de la Parfumerie** (Fragrance Industry Dinners) for La Fondation Motrice, taking advantage of my professional network within the perfume and cosmetics industry. These yearly dinners welcome about 200 actors from this sector, under the patronage of Andrea Casiraghi.

I wish that people from other industries help us promote and extend this idea and organize Bank/Insurance, Pharmaceutical Industry,



Daniel and his daughter Camille at the arrival of the 2011 Heroes Race.

Media, High-tech Dinners, etc.: research on cerebral palsy needs their help!

Daniel Chastenot de Géry

45
projects
supported



60
articles
published



2M€
allocated

OVERCOMING THE CAUSES AND CONSEQUENCES OF CEREBRAL PALSY,

**THE MOST FREQUENT MOTOR HANDICAP IN CHILDREN
1 OUT OF EVERY 450 NEWBORN IS AFFECTED.**



La Fondation Motrice goals:

- promoting and supporting research and innovation in any field likely to help prevent cerebral palsy and improve the quality of life of those affected by this condition;
- improving the quality of care, promoting good practices and developing our knowledge of cerebral palsy.

Right from its inception, La Fondation Motrice has worked in the medical field, through **calls for research projects** subject to the assessment of its Scientific Committee. La Fondation Motrice also organizes **Information and Study Days**.

Furthermore, La Fondation Motrice has conducted in 2008-2009 a **prospective study** to gain a better understanding of the needs and expectations of both the patients and their families to be able to guide the strategic orientation of the research effort. This study, supported by the CNSA, relied mostly on multidisciplinary workshops in which participated patients and members of their families, researchers, health professionals and carers.

Based on the study results, La Fondation Motrice has prioritized the following **fields of action**:

- **Pain**, as it is a major problem for CP patients (cf. inside pages);
- **A holistic view of the individual and its complexity**, taking into account the role of environment. This is where PACE plays a part, an innovative program implemented with the support of SODIAAL (cf. inside pages). Research on patient's life as they grow up, and particularly when they reach adulthood, is underway within this program;
- **Prevention of brain damage.**

➔ **La Fondation Motrice is supported by FFAIMC, the French federation of cerebral palsy associations.**

➔ **FOUNDERS**
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Fondation Reconnue d'Utilité Publique par décret du 4 juillet 2006

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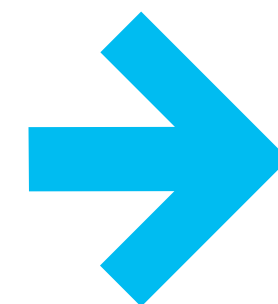
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ANNIVERSARY ISSUE

Infomotrice



THE FUTURE IS IN YOUR HANDS

Dear friends,

La Fondation Motrice for research into Cerebral Palsy is focused on the most frequent motor handicap in children as **1 child out of 450** suffers from cerebral palsy.

In 5 years, La Fondation Motrice has contributed to make cerebral palsy a major subject for **dedicated teams of researchers**.

Thanks to your help, 45 projects in Europe have been financially supported through La Fondation Motrice. About 60 articles have been published in international scientific journals to demonstrate how to reach a better understanding of brain damage, promote early treatment, reduce abnormal movements or develop technical aids.

For the first time, also, handicapped youngsters, their families and their helpers have been able to talk with researchers to highlight the most urgent expectations. We have learned, through this dialogue, what it means to give everyone a place and **to see in each individual what he or she is able to do instead of what he or she cannot do**. **All of you who support our action can be proud of what has been accomplished.**

This anniversary is also an opportunity to thank those who joined and supported us in this adventure.

We are deeply grateful for your wonderful contribution: you have all greatly contributed to our results!

Today, we are looking to the future. Preventing brain damages, relieving the pain, improving motor and cognitive autonomy, and facilitating

daily life: those are our goals, but **until when will we have the means to attain them?**

The resources contributed by our founding members to set up La Fondation Motrice have all been used.

Donors and friends, today, the key to our future is in your hands. Your donations, your commitment will determine our success: **what La Fondation Motrice will be able to do depends on you**. Each of you can relay this message and each of you will respond as you will see fit.

La Fondation Motrice brings together handicapped persons, researchers and donors around shared goals. Everyone has a place in this project and everyone is part of our future: **we invite you to participate in this beautiful adventure and to share its success!**

Thank you.

Alain Chatelin, President

BRAIN DAMAGE IN NEWBORNS PREVENTION OF BRAIN DAMAGE

➔ Research on brain cells and molecules involved in brain damage.

Vincent DEGOS, Pierre GRESSENS. U676, Physiopathology and neuro-protection against brain damage during pregnancy. INSERM, Université Paris Diderot - Robert Debré Hospital, Paris.

Our laboratory's principal activity is focusing on brain illnesses and diseases in children, with a view to discovering new treatments.

The most important illnesses are those occurring at birth and concern mainly premature babies. To this day, no treatment exists for these illnesses. We are trying to identify which cells and molecules play an important part in brain damage, to be able to target mechanisms that would allow to block off the damage process.

This research, supported by La Fondation Motrice in 2005 and 2006, has in particular identified inflammatory mechanisms playing an important part in newborn brain damage and has put in evidence the neuroprotection provided by some glutamate receptors blockage.



➔ Research is making progress!

Based on studies of animals, in particular in Pierre Gressens's laboratory, a clinical test to assess neuroprotecting effects of melatonin in premature newborn has begun in London, in collaboration with this laboratory.



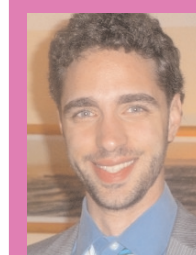
IN BABIES

EARLY CARE THROUGH SCREENING

➔ Implementation of assessment tools for cognitive and perception problems: PACE program (Perception Action Cognition Environment).

To see a person as a whole, taking into account all interactions with his/her environment, such is the challenge of PACE program, that considers motor, cognition and perception problems as closely related and reviews their connexion to cerebral palsy.

Within this framework, several studies aim to implement assessment and screening tools for these problems in children and in particular in babies. The first year after birth requires a lot of vigilance as it is



We are expecting a baby girl and we follow her development with utmost attention, week after week. The human body is an extraordinary piece of machinery, very complex and strong but also very fragile: knowing and protecting it is a huge challenge. As any parents to be, preventing risks and improving our child's health is our duty and each progress in research is a step further to protect young lives.

David

PAIN IN CHILDREN

UNDERSTANDING AND HANDLING THE PAIN IN ORDER TO IMPROVE THE QUALITY OF LIFE, NOW AND IN THE FUTURE.

➔ Creation of a pain observatory in children and teenagers.

Professor Olivier REMY-NERIS, in charge of Physical and Rehabilitation Medicine, CHU Brest (France)

The phenomena of pain in children and teenagers are often unrecognized and in France we do not have enough studies regarding this issue.

With the creation of a Pain Observatory, our main goal is to assess the frequency (i.e. the number of affected persons) of pain within this population of children and teenagers.

To implement this project, La Fondation Motrice has called on a group of experts from various fields specialising in Physical and Rehabilitation Medicine, pain, neuropediatricians, psychologists and physiotherapists.

In particular, we aim to
- assess pain frequency during daily life movements as well as the fre-

quency of spontaneous pain;
- analyse the link between pain and severity level of CP;
- describe how pain is treated through remedies or other means, and parents' reaction when their child is in pain.

The Observatory, which will rely on pain assessment by the children, their parents and health professionals, will provide us with a better understanding of pain and therefore give us some directions to mitigate it.



➔ Researching pain linked to orthopaedic complications.

Dr. Isabelle POIROT-HODGKINSON, specialist in functional rehabilitation for children, Escalé hospital, Lyon (France)

Children with cerebral palsy and in particular those who are able to walk have a high risk of hip dislocation and scoliosis likely to cause a lot of pain. The causes and mechanisms of such pain are not yet fully recognized.

Therefore we have launched a long term study covering a wide field: during

10 years, we will follow 385 children between the age of 4 to 1 (160 were already registered on the 1st of November 2011) and observe the evolution of pain, posture, hip deformation, rehabilitation programmes implemented and every factor likely to influence their hip problems.



Since I had the operation on my leg, the pain is considerably reduced and I take fewer remedies. Before the operation, my knee was very painful at the end of the day, or after I had a sport activity. But it is when I was in hospital, right after my operation, that the pain was the worst. I was lucky to have a morphine pump that I could activate myself and also my parents were with me. That was a great help to get through all this!

Louis, 14



IN TEENAGERS

TO ACCOMPANY THE PASSAGE TO ADULthood.

➔ A study on social support and the quality of life of teenagers suffering from cerebral palsy.

Dr. Catherine ARNAUD, UMR Inserm U1027, Paul Sabatier University, Toulouse

We still have a very limited knowledge of how teenagers affected by CP live with their handicap and face the difficulties they encounter in their social interactions, their life at school and the kind of jobs open to them.

Early studies show that at that age, health and wellbeing seem to be more dependent on social and environmental factors than on medical care. It also seems that social support helps reduce the perceived stress and brings about a global improvement of physical and mental health and a

wider and better autonomy.

Our study aims to assess the part played by social support, be it from family members or friends, to improve CP teenagers' quality of life and to determine the extent to which they require such support, as it reflects their capacity to adapt and be autonomous. We focus in particular on support from the family and the kind of help supplied by siblings, as the case may be.

To this end, we observe a group of 60 teenagers aged 13 to 17 and we conduct interviews with the

families of at least half of them. Our goal is to describe subjective experiences as well as the objective health of this population that is not well known. Measuring the importance of social support, in particular from the family, as a factor of perceived well-being would be useful to accompany teenagers with CP and thus improve the quality of their lives.



The way to a better life is to invent the "CP Way of Life": to feel good as a handicapped person, discover one's strengths and weaknesses without "imitating" at all cost the way of live of valid individuals. This implies a positive accompaniment, a supportive and reassuring social and medical environment as well as constant care to reduce the pains.

Richard

IN ADULTS

IMPROVING LIFE AND AUTONOMY BY REDUCING RELATED PROBLEMS AND SUPPLYING TECHNICAL AIDS.

➔ A study on deep brain stimulation impact on abnormal movements in some forms of CP.

Pr. Marie VIDAILHET. CRICM UMPC/INSERM UMR S975 CNRS UMR7225, Neurology and Care, La Pitié-Salpêtrière Hospital, Paris

Preliminary research has shown that deep brain stimulation at high frequencies in particular of the inner pallidum, one of the ganglia at the base of the brain, helped to reduce limbs' abnormal movements without undesired side effects, in dystonic patients.

Cerebral palsy resulting from brain damage often causes dystonic movements of the limbs, body and face that can induce joints and bone deformations and hinder to a large

extent the life of patients. To this day, the treatment of these problems was not very effective.

In this pilot study, we have been able to demonstrate that stimulating the inner pallidum can also be used effectively on patients with cerebral palsy to improve their quality of life by reducing their handicap and pain. This new approach will need validation on a larger scale and longer term.

➔ Assessment of aids to communication.

Philippe BOISSIERE, Institut de Recherche en Informatique (Institute of IT Research), Toulouse.

Several systems to facilitate communication have been developed recently, based on different techniques or interfaces, but they have not been subjected to comparative assessments.

Measuring the quality of this kind of aids in relation with specific needs of CP patients unable to speak would open the way to the development of more efficient software solutions.

This project is continuing today with PALLIACOM program, financed by Agence Nationale pour la Recherche (National Agency for Research).

Myriam, Lucie's mum