



LA FONDATION
MOTRICE
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A COMMITMENT TO REACH REALISTIC DREAMS

La Fondation Motrice is dedicated to preventing all forms of cerebral palsies and improve the quality of life for all patients suffering from the condition. It is defined by three roles¹ and aims to be:

- a pole of expertise through its Scientific Council and its teams;
- a pole of means, through financing and the networks that it contributes to build;
- a speaker as communication is not the least powerful of tools to represent the

patient's expectations and hope.

Right from the moment when it was created, la Fondation's aim was to place the handicapped person on the forefront, by giving several young patients the possibility to address the researchers via an Alexandre Agnès's film that was broadcasted during our first convention in Collège de France. Building a vision to guide our action was essential. That is why we have launched in 2008 a prospective study to identify the expectations of all the individuals concerned by cerebral palsy, by presenting them with everything that could be done in the short, mid or long term, to determine essential fields to support and to identify the future messages content. The French organization to promote autonomy (Caisse nationale de solidarité pour l'Autonomie) recognizing the novelty of our initiative, asked to be the principal partner of this study. La Fondation Motrice completed the financing and another organization supporting solidarity (Caisses d'Épargne pour la Solidarité) provided financial support for a workshop.

A considerable amount of work has been accomplished by the team² and about 140 people, patients with their families and the professionals that help them, on one part, and researchers on cerebral palsy or related fields, on the other part, have participated with great enthusiasm to a series of workshops. Every voice has been listened to. Questions concerning research efforts were classified in different thematic categories, five of which have already been subject to a detailed review. You will be able to judge the quality of the results, but a new light has been cast on several things.

Some factors were neglected because they have become part of everyday life (like pain). The strongest expectations concern fields where biomedical sciences will need to employ their most sophisticated techniques (brain damage, for instance) but also aspects related to social sciences or medical and social assessment (individual's coordinated path), which La Fondation has not yet approached. Expectations are very often highly altruistic (hence the importance granted to prevention and for those who can speak, to communication). Handicapped persons and researchers had a very rich dialogue and exchange : to build "an ethic of shared freedom" is a phrase which I borrow from other, more relevant, sources³ but that best characterize how each one, whether patient or researcher, recognized the other in his or her being and his or her role.

However, this new scope, this new construction that we have discovered, will find their true meaning in the commitment they will create.

It falls to us, to you, to everyone to mobilize so that these expectations and opportunities come first in our action and to provide the means to progress and reach these realistic dreams. Thank you to support La Fondation Motrice with all the energy they need!

Dr. Alain Chatelin, Chairman

¹ André Rey, then a Director, was the first to clarify these fields of action and encouraged us to launch this prospective study.

² GERPA (Régine Monti et Pierre Chapuy), prospective experts, a project manager, Daniel Ejnes, assisted by Elisabeth Choplin working under a Steering Committee representing La Fondation Motrice, CNSA and various experts : Emilie Delpit, Francelyne Delyon, Pascal Jacob, Bachir Kerroumi, François Revol, Louis Vallée and myself. A heartfelt thank you to all of them !

³ I hope that the author of that remarkable book will forgive my borrowing it from him : E. Zucman, *Auprès de la personne handicapée. Une éthique de la liberté partagée.* – Vuibert.

What do patients expect from research on cerebral palsy?

Pain

"Pain makes my life miserable"

Relieve the pain comes first in terms of needs: incorrectly diagnosed and taken into account, pain is nevertheless the first reason to go and consult a doctor and renders everyday life a lot harder.

- *Identify pain mechanisms in CP patients and their specificities.*
- *Improve treatment of pain related spasticity or hypertony.*
- *Find efficient and specific molecules with less secondary effects.*
- *Make detection systematic, communicate and create centres to fight the pain.*

Ageing, tiredness

First and foremost: it is urgent to recognize and obtain recognition for cerebral palsy

Although it is the first cause of motor handicap in children and that it affects 125 000 persons in France, cerebral palsy still remains little known not only by the general public but also by the health professionals.

The study shows a need to:

- reach a denomination and a definition understandable by as many people as possible. Today, various denominations coexist in France, such as IMC, IMOC, polyhandicap to name a few, each of which corresponds to a medical reality but could be merged into the same definition ;
- widen communication related to this pathology, both very specific and very diverse;
- introduce cerebral palsy in medical schools cursus and implement a training and continuous learning programme on the pathology for health professionals.

Lesion

"If it is not discovered for us, let it be for others in the future"

Increase knowledge on causes and mechanisms of brain lesions is at the heart of research: will it be possible in the future to "repair" a damaged brain?

- *Reach a better understanding of how lesions occur to prevent them.*
- *Promote early detection to improve diagnostic and treatment for newborns.*
- *Improve brain imaging and provide it to affected people to have a better understanding of their lesions and their capacities.*
- *Explore the possibilities of new therapies.*

Treatments, associated disorders

Cognitive disorders

"It is everything that connects me to the environment that has not been properly dealt with."

Above all: communicate about cognitive disorders and their nature: cognitive disorders (related to learning, movement, memory, attention, language...) are misjudged and mistaken for mental deficiencies. They are often related to motor disorders. They are little known and therefore not always correctly diagnosed.

- *Discover the reasoning and acting mechanism of a damaged brain.*
- *Improve knowledge on the relationship between cognition/motricity/language.*
- *Reduce spatial and temporal orientation and localisation disorders, improve speed of execution*
- *Improve cognitive rehabilitation-readaptation.*

Language

"Communication is easier at the post office than in the emergency services".

Improve communication to improve understanding et eliminate the confusion with word/language: even though new technologies have brought enormous improvements, CP patients still have the feeling they are considered as mentally retarded.

- *Understand how words take form in a damaged brain: is it possible to "dig them out"?*
- *Improve knowledge of the connection between language and motricity.*
- *Facilitate speech, understanding and data capture.*
- *Define rehabilitation programmes and technologies adapted to each individual.*
- *Accelerate technological innovation: Brain Computer Interface, language/computer interfaces, voice synthesis, etc.*
- *Reinforce speech therapists training, develop links with Ministry of Education.*
- *Consider the creation of a new profession of Communication Facilitator (cooperating with APF).*

Psychology and relations with the outside world

Mobility

"My wheelchair is like my second skin"

An improved mobility is an "obvious" expectation in the case of motor handicap. But this need varies with the patient, whether he is able to walk or uses a wheelchair, and is also related to other aspects like accessibility, transport and financial means. *"Why speak of autonomy when it is impossible to go to a movie with friends without planning it 3 weeks in advance?"*

- *Improve walking and make it more aesthetic.*
- *Improve body movement coordination and posture.*
- *Develop wheelchairs so that they become like a second skin through personalized options: micromovements, SATNAV with obstacle alert capacity, remote communication and control, etc.*

Prospective study identifies 13 priority lines of reflection

Upstream: raise awareness of cerebral palsy and obtain recognition of the condition

1. Pain, spasm
2. Autonomy, mobility, accessibility, wheelchair
3. Speech and communication
4. Cognitive disorders
5. Lesion : understanding, prevention, treatment
6. Ageing, tiredness
7. Therapies, associated disorders
8. Psychology, communicating with the outside world, self-image
9. Individualized path, Ministry of Education, access to a job
10. Interdisciplinary approach of treatments and research
11. Technology and engineering sciences
12. Assessment
13. Access to validated data

CALL FOR RESEARCH PROJECTS 2009

- Cerebral palsy in children and adults –

Any applied or technological research project aiming to improve knowledge, prevention, treatments, rehabilitation and readaptation of CP patients.

In particular, projects undertaken in cooperation with a care and therapy team will be encouraged. European projects including one or two French teams will also be considered a priority.

Applications can be for :

- research grants (Master, doctorate, post-doctorate) with related activities (conference and publication costs),
- temporary staff

Furthermore, an advanced project in clinical or translational research could received financing up to 100 k€ :

- including staff and operating costs
- non included equipment costing more than 15k€.

Application forms can be downloaded from: www.lafondationmotrice.org

Deadline to file applications: May 1st, 2009.

Contact :

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Introduction

This study led in cooperation with GERPA, a prospective expert company, is a so-called “qualitative” study. The goal of this type of study, based on individual or group interviews, where listening to participants is crucial, is to identify their expectations, requirements and motivations. Several workshops were organized which allowed us to bring to light major themes and questions which need to be further investigated.

Contrary to a “quantitative” study, based on forms distributed to a representative sample of the targeted population which allow to make assessments and statistical calculation, the results of this study are not quantified.

The study took place during 2008 with several workshops in which 140 people participated, all of them concerned by cerebral palsy:

- patients and their families
- researchers
- health and care professionals.

Scientific and medical experts were asked to comment and detail the various themes and questions addressed during these workshops.

The prospective study by La Fondation Motrice received a financial contribution from Caisse Nationale de Solidarité pour l'Autonomie.

