



What expectations and what motor rehabilitation priorities for persons with Cerebral Palsy ?



Editorial

By launching a nationwide investigation on perceptions of motor rehabilitation and their expectations and priorities in this domain, La Fondation Motrice, in partnership with the French Federation of Associations IMC (FFAIMC), stands once again with the persons affected by Cerebral Palsy- for whom motor rehabilitation is part of the care they receive their whole life- and with their families. A prerequisite for the elaboration of good

practice, this investigation is consistent with our main objective: improving lives of the people affected.

In charge of coordinating the Committee's work, Geneviève Geyer and myself are extremely grateful to its members for their participation in this project, and very honoured by the support from the four organisations concerned (CDI, SFERHE, SFNP and SOFMER), a sign that our approach has purpose and scientific credibility.

Inspired by families, built with their help and based on their feedback, this innovative investigation will allow us to bring to the foreground the research projects that meet the expectations of those concerned. It is crucial.

Dr Maria Bodoria, Scientific Director at La Fondation Motrice

An important national investigation on motor rehabilitation as perceived by people with Cerebral Palsy and by their families, launched in 2016, should bring to the foreground the needs and improvements expected in this field.

Why the investigation?

Motor rehabilitation includes physiotherapy, ergotherapy and psychomotricity. It is crucial, and is the base of care for people with Cerebral Palsy their whole life during.

To date, in France, there is a lack of best practice recommendations for motor rehabilitation, although we are generally turning towards Evaluation Practice and Evidence-Based Medicine. There is also very little information on what the people affected, and their families, really think.

Nonetheless it appears that families face difficulties in accessing motor rehabilitation across the national territory, and in finding professionals who have specific training with Cerebral Palsy.

In this context, La Fondation Motrice along with associations representing families (teamed together in the FFAIMC) found it important to lead an investigation with the people affected, and with their families, to collect their feedback on the subject.

This investigation, built with the help of a multidisciplinary committee, was supported by four organisations dedicated to the question of care for people with Cerebral Palsy in France (see the following pages). Its results will be a first step in the process of elaborating best practice recommendations: an essential tool to improve lives of those affected.

A very innovative approach

Such an investigation, in this topic, from the patient's perspective, is a first in France, and even in Europe if we consider the multidisciplinary nature of its study committee, as well as the fact that the families' needs were used as a starting point, and that the organisations in the relevant fields were integrated, all that in relation with the French High Health Authority.

A multidisciplinary study committee.

Representatives:

- **Persons with Cerebral Palsy:** Julia Boivin, Gaëlle Drewnowski
- **Families:** Eric Bérard (French Federation of the Associations IMC)
- **Field professionals:** Nathalie Chauveau (Notre Dame, Neuilly-sur-Seine), Audrey Fontaine/Dr Michel Thétio (Hôpital Saint Maurice, Sainte Maurice)
- **Learned Societies:** Dr Sylvain Brochard, Pr Isabelle Desguerre, Pr Vincent Gautheron, Yann Le Lay, Philippe Toulet (see the following pages)
- **La Fondation Motrice Scientific Council:** Eric Bérard (representing families), Dr Sylvain Brochard, Dr Javier de la Cruz
- **Coordination:** Dr Maria Bodoria, Geneviève Geyer

In charge of the preparation and follow-up of the investigation, the Committee is composed of 14 members representing all those concerned by motor rehabilitation.

The French High Health Authority was also consulted during the preparation of this study.

A central role for the persons concerned

Being the subjects of the study, persons with Cerebral Palsy (CP) and their families are also at the heart of the investigation management, with four representatives.

Eric Bérard, representing families.



I am a member of this Committee as the father of a 42-year-old man with CP, and as member of the bureau and of the board of directors of the French Federation of the IMC Associations. Moreover, quality of care is a huge obsession of mine, as I was a practitioner and spent 12 years working at the French High Health Authority.

The idea of this investigation started when I met with La Fondation Motrice. My role in this project is to catalyze the energies, to mobilise goodwill so a greater number of people take part in the investigation. I stand with families,

I want them to be able to express themselves, and at the same time I want this study to result in best practice recommendations for professionals. By combining the patient's account of what helps and what hurts, and scientific evidence on the effects of different practices, we will necessarily improve the quality of care, and thus the lives of people with CP.

Julia Boivin, 24 years old, representing people with CP.



My participation in this study committee is an extension of my commitment: I am a member of the Rhône-Alpes ARIMC ethics commission, and my first concern is to see disabled people becoming subjects, and not objects of care. This project is consistent with this fight: giving the floor to patients, not only professionals.

I plan to share my personal experience of liberal medicine, but also of

rehabilitation centres, and I will make myself the spokesperson of all those who need rehabilitation for their whole life. My account is also enriched by the observations I was able to make in my studies, in particular during my Master's degree in « Handicap and Autonomy » when I was working on rehabilitation practices in specialized centres.

I really hope that many will answer this investigation truly and sincerely. Patients are rarely given the chance to speak up, we cannot miss this occasion. I may be over-optimistic, but I really think this study can lead to serious thinking about what physiotherapists do and what the physio-patient relationship should be. We have to bring back some humanity in care, which for now remains way too medical and mechanical.

Learned organisations are listening

In connection with the reflection on the implementation of best practice recommendations in motor rehabilitation for professionals, this study was elaborated with the active support of four organisations dedicated to the question of care in Cerebral Palsy in France.

A learned organisation is an association of experts who, by their work and their exchanges, make knowledge progress in their field. It can be multidisciplinary, like the SFERHE, whose members represent all fields concerned with child handicap, or specialized in one field, such as neuropaediatrics for the SFNP.

Organisations represented in the study committee:



CDI.

Documentation and Information Center on rehabilitation for people with cerebral motor infirmity



SFNP.

French Society of Neuropaediatrics



SFERHE.

French Society of Research and Study on Childhood Handicaps



SOFMER

French Society of Physical Medicine and Rehabilitation

Dr Sylvain Brochard

Pediatrics, physical medicine and rehabilitation. Member of the SFERHE and the SOFMER.

This study is very different from what we usually do. Its main purpose is to bring us knowledge about the children's and parents' needs in the field, which is a big motivation.

We will collect lots of data. Once analysed, this will give us an evaluation of the needs and practices, and an idea of the quantity and quality of rehabilitation received. It's a key step to practice recommendations that really meet the needs.

For the SFERHE, because of our interest in child handicap in general, this study is important: what we will learn on CP, the first cause of motor handicap in children and the first reason for consultation in pediatric PMR, will of course be useful to other pathologies.

Pr Isabelle Desguerre

Neuroepidiatrician. President of the SFNP.

Neuroepidiatricians are prescribers of rehabilitative care, so we are very interested in an evaluation by patients themselves, and by the experience of children and parents. We know, among other things, that pain is badly evaluated and that we need a new vision.

At first, this study will be a basis for reflection and discussion within learned societies, or in universities, and even if it's only a first step to being able to make recommendations, it's an important one. This greater picture, once established, will be a formidable tool to go see the authorities and show the strengths, as well as weaknesses, of the provision of our care.

Pr Vincent Gautheron

Pediatric physical medicine and rehabilitation. Member of the SFERHE and the SOFMER.

I have been concerned with questions relating to rehabilitation practices since the start of my career, 35 years ago. Do we improve quality of life in the people affected? Do we take into account care-induced pain? Sometimes we do things for the future, and forget about the present. We put lots of energy in care, but the question remains: what is the sense of what we can offer?

Today, we cannot content ourselves with our predecessors' experience. We need evidence that what they were doing was legitimate and interesting. This study may show us that our opinions are ready-made, perhaps wrong, and we should prepare to question it, based on the experience of those concerned, both children and adults. One particularly important question is in relation to pain, the one caused by care, and the one due to the natural evolution of CP.

Philippe Toullet

Physiotherapist. Member of the CDI.

For the CDI, this study on rehabilitation is very important since we are particularly concerned with the subject. Indeed the CDI is very involved in rehabilitation and its two representatives are physiotherapists.

The other point is that the study gives families, with whom we have a privileged relationship, the occasion to speak up. And this picture of quality of care as they perceive it deserves to be taken into consideration. This way the profession can progress, as well as competencies in matter of know-how and social skills.

« By being a part of this investigation, we can change lives! »

Eric Bérard, representing families in the Study Committee

From May 2016, people with Cerebral Palsy and their families will be given the opportunity to answer a questionnaire about their expectations regarding motor rehabilitation. The more respondents there will be, the more reliable and representative the information collected on everyone's needs and priorities in this field.

Who can participate?

- People with Cerebral Palsy (or CMI, hemiparesis)
- Parents or close family when the person affected isn't able to answer him or herself
- All ages are concerned- children and adults
- Whether or not they benefit from motor rehabilitation sessions at the moment of the investigation

How to participate?

- To participate, one just has to fill the questionnaire available online on a secure website dedicated to this investigation, accessible from La Fondation Motrice website: www.lafondationmotrice.org
- People who want a hard copy of the questionnaire can ask for it by email (enquetefamillereeducation@gmail.com) or by post (Kappa Santé, 4 rue de Cléry, 75002 Paris), while indicating how old is the person with CP (certain questions depend on the age bracket).
- Answering the questionnaire takes about 30 minutes
- Data will be collected anonymously and on a confidential basis so it will be impossible to identify any respondent.

The research institute Kappa Santé, specialised in epidemiology, pharmacoepidemiology as well as public and numeric health was given the responsibility of the management of the investigation.

For more information, see the brochure available on the following websites:

- www.lafondationmotrice.org
- www.faimc.org
- www.hemiparesie.org
- www.cdi-infirmitemotricecerebrale.org
- www.sferhe.org
- www.sfneuroped.fr
- www.sofmer.com

Study Schedule

- May 2016: launching of the investigation and online publishing of the questionnaires
- May to December 2016: collection and processing of the questionnaires
- Last quarter of 2017: results will be published progressively on the foundation's website: www.lafondationmotrice.org. The investigation requires about a year for data collection and analysis.

More information on www.lafondationmotrice.org

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