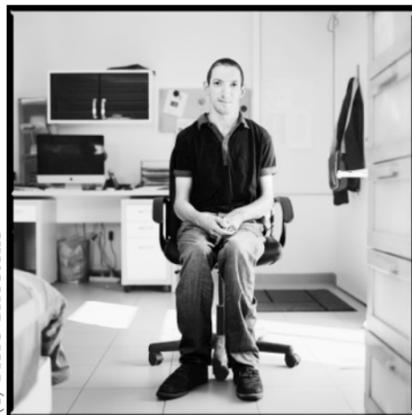


Living with cognitive and perceptive disabilities.

→ **Guillaume, computer graphics designer: “I’m still embarrassed when it comes to mentioning my handicap to my clients”.**

Besides my motor problems, I’m suffering from joint problems, and also from dysorthographia (I have trouble following spelling rules although I know them) and dysgraphia (I have a bad handwriting). This was a problem when I was in school, and it remains a source of embarrassment at work. My dysorthographia appeared when I learnt reading and writing, and even if I was told that it was related to my handicap, I had trouble admitting it: during my whole school years, I had bad marks in French because of my spelling.



(c) Flore Tricotelle

It’s the same today: it’s hard to explain I can be a good graphics designer, even if my spelling is bad. In this job, you’re supposed to spell correctly.

I haven’t found how to solve this problem yet. Professional softwares do not include a spell checker, and my joint problems prevent me from using voice recognition. These joint problems are also an issue when I have to call my clients: phone calls make me nervous, which amplifies the handicap, and the first contact is often uneasy. I’ve already had people hanging up on me! If I had to choose, in priority, I would like to find a solution regarding my spelling problem: I must admit that mentioning my handicap to my clients is still embarrassing.

↙ **“I felt myself totally helpless”. Jean-Paul, father of triplets.**

Among the different cognitive disabilities my children are suffering from, the most important today would be neurovisual troubles, which were correctly diagnosed only six months ago, whereas they constituted a real handicap for them during their whole school years. One example that really moved me is my daughter’s troubles with geometry: in sixth grade, she didn’t close her triangles. When I found this out, I felt totally helpless, and I even feared that she wouldn’t make it to seventh grade.

When they were young, I didn’t know how serious their lesions were, and even less what the repercussions of Cerebral Palsy, other than the motor ones, would be. I found that out myself, as they were experimenting, more and more, their cognitive troubles. Few doctors, and it was even truer a few years ago, are aware of all the aspects of Cerebral Palsy. Sometimes these troubles are detected, but they are still considered less important than the motor issues, since they appear not so severe a handicap: thus

complementary treatments are often forgotten, while they are more efficient when started early. This is what one of my sons is dealing with. He is currently starting a rehabilitation to learn how to read: it will be, I believe, less efficient than if he had started earlier. I believe early diagnosis to be a top priority.

The PACE program



With the PACE program, facing the double challenge of early detection and understanding of troubles generated by Cerebral Palsy.



Dear Friends,

When reading Guillaume and Jean-Paul’s stories (page 4), one can’t help being moved by the impact of motor disability on daily life. This shows how important **an early detection of cognitive and perceptive disorders** is. **With the PACE program (Perception, Action, Cognition, relation with the Environment)**, La Fondation Motrice aims to better understand children’s development and coping of the disorders generated by Cerebral Palsy.

The definition of Cerebral Palsy has evolved, as Pr Giovanni Cioni stated at the family information day held for the foundation’s fifth birthday.

Only motor disabilities were considered 40 years ago; today’s definition also includes sensory, cognitive and communicational disorders, all essential factors in understanding motor disability, since motor ability and cognition are related.

To understand and address Cerebral Palsy we need **to develop tools for early diagnosis**, to make possible a better screening for this disability, and a proper rehabilitation.

This is how the PACE program was born, when a number of **European research teams of excellence** started networking. Thanks to the Sodiaal Company’s donation, we were able to fund the start-up phase (team coordination,

multidisciplinary thinking), and to launch the “pilot” study (pages 2 and 3).

Now it is for us to take over, to provide the teams with the necessary tools and to launch a call for proposals with new teams.

This is the foundation’s mission: to be at the crossroads between the ones suffering from Cerebral Palsy, scientists and donors, and to launch new research projects that address the main concerns expressed by the handicapped and their families. **Without your donations, without the commitment of La Fondation Motrice’s friends, this mission would remain unfulfilled.**

On behalf of the children, on behalf of the research teams, thank you for your unwavering support.

Sincerely,

Dr Alain Chatelin, President