

Victories that we will attain together

Dear Friends,



When reading about Arthur's mum, Aurélie, and Marie-Francelyne, in this letter, I am first of all reminded of the generosity these women, and their commitment. By developing services or making progress in research, they are honoring the associative vocations. They tell us to what extent the troubles they are affected by affect their ability to act, as well as social handicap, and the pressure other people's reactions can entail.

Diane, Catherine, Marie and Philippe, doctors and researcher or physiotherapists, explain how their focused attention is already allowing for partial treatment of some movement disorders, as well as advancing in the search for the difficult equilibriums before better treatments are available. Aside from their exceptional competence, what really comes through when they meet with their patients is their humanity. They would like to do more, but research is still lacking the resources.

The Foundation is expanding, as you will see in our "News" page. Pierre-Guy, our director, Claire, our communicator for charitable sporting events, Geneviève, working for industrial partnerships, and Christine working on the database, have decided to get involved with the foundation as volunteers, thus bringing us both their expertise and their energy. Their friendly attention is a mark of trust for everyone who feels concerned with Cerebral Palsy.

Pr Marc Tardieu has accepted to help us in the following months with renewing our Scientific Council, whose role it is to evaluate the projects asking for our support. It is time to express our gratitude to its loyal members, and to welcome the new ones.

All the family associations we meet stress the importance of the Foundation as an organisation which mobilises and opens positive perspectives.

We also wish to express our thanks to our sponsor Andrea, whose friends met together in spring, thanks to Daniel, who brought along the French perfumery to dinner in October, thanks to our partners (Sodiaal, CNP Foundation, TFWA, Fonds Emeraude...), thanks to the runners' energy at the Heroe's Race, and finally our donors, thanks to whom two majors axes of progress -the pain of children, and the entanglement between motor, perceptive and cognitive troubles,- benefited from the attribution of research grants this year.

There still are challenges to face: they are in your hands. Whilst our children show amazing courage daily to keep their place in society, despise its inertia and indifference, whilst the medical staff along with researchers accomplish so much to make barriers to their development disappear, it is also your generosity that decides on what La Fondation Motrice can do. We thus want to thank you for your renewed commitment. Merry Christmas and thanks to all!

Alain Chatelin, President

Finding solutions against movement disorders: **a challenge for research, a necessity for the patients concerned**

Among the troubles associated with Cerebral Palsy, we often find “abnormal involuntary movements”. Affecting the limbs, the core or the face, they can lead to joint and bone deformations and seriously affect the patients’ life.



Still too few solutions for patients



Dr Dianne Doummar, Neuropediatrician, Trousseau Hospital, Paris

Movement disorders can be observed in different forms of Cerebral Palsy: they follow an alteration of the basal ganglia, a major actor of motor functions, whatever the cause of the damage. They can result in a dystonia (parasitic spasms, abnormal postures), a chorea (permanent random movements) or jumps.

According to the zone concerned, they can also affect walking, through badly positioned feet, create difficulties in prehension (upper members), elocution (the larynx muscles), etc. These movements, that affect voluntary movement are aggravated with stress and emotion and, whilst they do not directly provoke intellectual damage, they can, according to the extent of the damage, add on to an intellectual breach, which is sometimes hard to evaluate.

Reducing movement disorders would allow to reduce social and orthopedic complications associated with Cerebral Palsy, but therapeutic resources remain limited. Reeducation helps find strategies that allow to bypass motor difficulties, and there exists treatments that act on the symptoms. Thus, botulinum toxin can act locally to make an abnormal position (squeezed hand, stiff leg...) disappear, and other drugs are used in case of generalized abnormal movements: L-Dopa, trihexyphenidyl or tetrabenazine, especially for hypercinesia. But everyone responds differently to medication, and when it fails, or when side effects appear (drowsiness, dryness of the mouth, for instance), one must try another molecule. For this reason, we need research to find new molecules.

Giving access to more drugs thanks to therapeutic trials



Dr Catherine Chiron, Neuropediatrician and Research Director INSERM, Necker Hospital, Paris

Finding new drugs, especially for children, requires the development of therapeutic trials. Yet there still exist reluctances, often out of misunderstanding.

A good drug must be both effective and non-toxic. What we seek is thus a good “benefits/risks” ratio, something which a trial allows to evaluate. The current climate, influenced by some recent mediatized events, tends to favor a “zero risk” policy, but there is no such thing, and patients need to get efficient drugs when their side effects are known and controlled.

When parents worry about seeing their child being part of a trial, they don’t realize the risks a no-trial policy would inflict on them. Only trials allow to detect and measure risks, and thus bring safety to those who will use the drug. Today, everything is done to make trials more efficient and “low cost” for children, for instance by reducing the number of samples, while raising the population tested, or on the contrary by using new mathematical models to reduce the test population. The 2006 European regulations demand that every new drug developed for adults be tested for children as well. It also contains incentives in order for the pharmaceutical industry not to neglect rare diseases. Thus the New Drug Application of an efficient drug for Huntington chorea led to a debate on the establishment of a therapeutic trial for children. This trial is still on, with the help of La Fondation Motrice, as it takes time and money.



Extending deep cerebral stimulation to certain cases of Cerebral Palsy



Pr Marie Vidailhet, CRICM UPCM/INSERM UMR_S975 CNRS UMR7225, neurology and therapeutics, La Pitié-Salpêtrière Hospital, Paris

For patients suffering from certain forms of dystonia, deep cerebral stimulation at a high frequency of the intern globus pallidus allows to reduce movement disorders with no side effects.

This concerns cases of dystonia that are said to be “primary”, in other words, without other neurologic anomaly and with a regular MRI,

for which this treatment is now largely developed and validated. This technique also proved its efficiency for certain genetic forms of dystonia, along with forms associated with long-term complications following the use of neuroleptics, for patients who are intellectually and psychically unharmed. By contrast, in children as well as adults, the results are more difficult to foresee for the dystonias that are said to be “secondary”, that is to say related to a cause, associated with other neurological troubles and with a MRI that can be altered. Cerebral Palsy, as a form of secondary dystonia, poses many questions regarding deep cerebral stimulation.

In a pilot study, we were able to show that this technique could be used efficiently for certain forms of Cerebral Palsy. Its efficiency, nonetheless, remains modest, and this treatment is not indicated, for instance, in case of prominent spasticity (involuntary contractions) or serious cognitive troubles. This new approach has been validated by other teams, who also insisted on the variability and relative modesty of the therapeutic response (20% on average). This intervention is thus decided individually, after a long discussion between the patient, his acquaintances and the medico-surgical team. The objectives must be fixed clearly, and the limits to the technique acknowledged. Indeed, whilst large movements of the neck and the trunk can be improved, it is difficult to be sure regarding the upper limbs: whilst the amplitude of intense movements can be reduced, the results are more dubious for the more subtle movements. Nonetheless, there are patients that observe better well-being, and manage to control their movements more efficiently, along with pain.

Research is still ongoing in all centers that are dedicated to dystonia and functional surgery, since the hopes and stakes are important. People with Cerebral Palsy have a good knowledge of their troubles: their expectations, their clear-sightedness, can be very precious for therapeutic discussion and research on movement disorders.

In the absence of treatment or as a complement: compensate and accompany with reeducation



Philippe Toullet, Cerebral Motricity Institute

When it comes to movement disorders, as for any trouble associated with Cerebral Palsy, reeducation tries to give the means to compensate, to find new automatisms in the gestures and to value the remaining potential. Every reeducation programme is personalized, and leans on a precise evaluation of the origins of movement disorders, in order to offer the best answer.

Thus, in a person whose involuntary movements appear during a specific activity, for instance when his arm is affected by gravity, will be offered to learn new support techniques for this limb, in order not to demand further efforts (than the one needed for the ongoing gesture). For another person, suffering from athetosis (uncontrollable movements while resting), the objective will be to ballast the arm with a leaden bracelet to force it to exert a more important strength (than the one exerted during parasitic movement). When the braking of the movements is ill-regulated by the cerebellum, as it is the case in the cerebellar syndrome, the patient will be taught how to divide his gesture into short sequences.

For all those affected, the stake is to regain control of their gestures while avoiding difficult situations. Today, reeducation is often one of the only answers to the problem represented by movement disorders.

Movement disorders: motor troubles, but also social handicap



Arthur, 12, in 7th grade, is suffering from movement disorder on a daily basis. Aurélie, his mother, tells us about it.

Besides the uncontrolled movements that happen when he experiences emotion or surprise, Arthur is made uncomfortable in the subtle motricity of his arm, which never remains still. He is unable to catch a small object and, in order to achieve a precise gesture, has to control the shaking arm with the other.

All daily gestures are disrupted: he breaks some things, he spoils others, he can neither write nor eat by himself. For him, it is more handicapping than not being able to walk, since his locomotion in electric chair is very agile.

There are technical aids, but then, he must choose between his autonomy and a social life. Thus, the “neater-eater” (a sort of articulated arm) that would allow him to eat is difficult to adapt to different environments and, at his age, his priority is to eat at the cafeteria with his friends. In the same way, computer systems designed for communication, that could help him compensate for his elocution problems, demand precision in handling, and since he is unable to type as fast as he thinks, he prefers to repeat what he has to say until we understand. Or he remains mute...

We haven't yet been proposed a drug therapy, but it's not an easy decision to make. After having tried an ineffective product, we now worry about the possibility of a dependency, which would force our son to stop the new treatment after 4 or 5 months, with no guarantee of finding a substitute. Then we are back to the starting point: that would be too hard to handle. Besides, what are the risks, if someone takes psychotropic drugs his whole life? No one has the answer, and we still don't know what to do. We therefore expect research to progress as our son grows. In that hope, we seek information in order to take the right decisions.



Marie-Francelyne, honorary representative of the Agriculture Department

On a daily basis, involuntary movements affect my social life much more than my actions. Even if they hide the well-controlled movement that I do in order to act, they rarely parasite it and I am relatively efficient.

But in public, the sensation of being watched increases the difficulty, and I have had to develop different strategies to put up with the gaze of others, to be able to live in society.

Thus, when I walk or when I take the public transportation, I take a book with me to hide my embarrassment (I can easily focus on a text) and avoid contact with the passengers (sometimes surprised, or even rejecting). I try to answer when I am asked questions, sometimes by a provocative remark that puts an end to the other's curiosity. Most of the time, I manage to minimize the incidents. But I don't always have the solution, and it has been an issue in a number of occasions. For instance, I often failed at oral examinations. When I took an exam to work in the university's administration, the jury's reaction was brought back to me by the social worker in charge of the handicapped at the CROUS of Paris. The CROUS director, who was in the jury and knew me well (my place was just above his office), tried to convince his colleagues I was capable to work as an attaché, but couldn't overcome the reaction of reject of these important and evidently very bright civil servants. This kind of incident happens on a regular basis, and has forced me many times to redirect my projects.