



## 2005-2015: 10 Years of Progress

La Fondation Motrice « Cerebral Palsy Days », taking place at the Pasteur Institute on March 13th and 14th, celebrated 10 years of progress in research on Cerebral Palsy. The event also reminded what should be the priority subjects for the years coming.



Leader

An important meeting for research on Cerebral Palsy, the event « Les journées de la Fondation Motrice » is also a place for exchange between researchers and the people hit, and the occasion to expose our priorities.

Two themes will mobilize our efforts in the months and years coming: evaluation of rehabilitation programs along with their clinical benefits, elaboration of recommendations and good practices. Medical imaging can be of help, by providing markers for rehabilitation analysis.

Prevention of Cerebral Palsy remains a key issue, particularly the question of direct therapeutic trials. Also important: the question of pain, as well as the field of robotics, absolutely crucial, in which progress must be made.

In this approach, we try to make sure that the people concerned are at the heart of research: they are now represented within the Scientific Council and co-animating the debates during these two days.

At last, we must be ready to use the results of the big programs on neurosciences that are launched today, in particular the one of the United States, which benefits from important funding and meets specialties, ready to answer questions on new technologies, and above all remain mobilized and open. Who would have foreseen, 20 years ago, the progress already achieved ?

**Pr Marc Tardieu,**  
**President of La Fondation Motrice Scientific Council**

**The comment of Anne-Catherine Guénier, President of the association Hémiparésie\*, mother of three children, two of them handicapped.**



\*[www.hemiparesie.org](http://www.hemiparesie.org)

The full contents of the event were fascinating, in particular the part about the newborn's neuroprotection, with many research leads including nutritional supplementation (Omega-3). Besides, moderate hypothermia in the first hours following birth seems to give good results for children suffering from cerebral damage. It raises questions: what about the children carried to term who had a CVA and whose Cerebral Palsy goes undetected for months, sometimes years ? Can supplementation of Omega-3 be efficient until later, and until what age ?

In matter of rehabilitation, mirror therapy directly concerns our association since our work is essentially about hemiplegic children. Our interest grew after we heard of Pr Pozzo's work at the event « Les journées de la Fondation Motrice 2013 ». So we contacted Pr Newman, who accepted to help us. We are also interested by Dr Dinomais' work on Medical Imaging, which made us understand that since all hemiplegic children do not have their brains reorganized the same way, certain rehabilitation methods, while beneficial for some, have no effect on others (it is particularly true of constraint-induced movement therapy). Physiotherapy sessions are critical for our kids, that's why I was particularly interested by the intervention of Philippe Toullet, with his method consisting in loosening the muscle (and the child) before exercise. We are willing to organize a learning session for the parents soon.

Finally, I was surprised by the simplicity and kindness of the practitioners and researchers at the conference, how they were willing to help our kids. As parents, we often feel like we are not really listened to, therefore we get anxious around the medical profession. Being with them during these two days was a great comfort. I think we are all ready to put a lot to help them, to participate to their studies as much as possible.

**Prospects for Cerebral Palsy: recent acquisitions and leverage for the future.**

*Pr Ingeborg Krägeloh-Mann, member of La Fondation Motrice Scientific Council, University Hospital of Tübingen*

We acquired these last years a better knowledge of Cerebral Palsy: we better know where it comes from, we better identify specific troubles, and thanks to a common language and the harmonization that took place, we can gather and compare data on an international scale.

We can affirm that there are definitely less children touched by Cerebral Palsy, thanks to the reduction in its prevalence among premature babies. It is a huge change that is not sufficiently taken into account. We are now able to handle Cerebral Palsy better, the education is better as well as interdisciplinarity between professionals.

We have evidence of neuroplasticity in the young brain (before 40 weeks of pregnancy) for the sensorimotor system and the language system. The hemisphere intact can replace the function of the hemisphere damaged (in the corresponding intact region), in a natural way, without treatment.

Treatments improve the life of the people hit: physiotherapy, hip surveillance (allowing to reduce hip dislocation) or percutaneous gastrostomy, which has a positive effect on bone mineralization and the reduction of fractures. After the first year, the treatment becomes specific and necessitates interdisciplinarity.

There is room for improvement in the next years regarding prevention and treatment:

- high-quality neonatology is crucial, it must be centralized, and efforts should be put in the field of neuroprotection
- for the child carried to term, hypothermia in the first hours following cerebral damage raises the survival rate, and the survival rate without Cerebral Palsy. We must now study this subject on an epidemiologic level
- the issue of preventing prenatal Cerebral Palsy isn't solved yet
- more studies are needed on pharmacotherapy
- and an important field of study remains: transition to adulthood, in particular what regards the loss of function for the people touched by the most severe forms of Cerebral Palsy.

*« Even if the lesion that first caused Cerebral Palsy is non-evolving, its effects, as for them, evolve in the course of life. We must find how to slow or prevent additional problems related to the growth, then the ageing of the person hit »*

*Pr Rachel Sherrard, University Pierre and Marie Curie, Paris*

### **Prevention Strategies: therapeutic trials of neuroprotection in perinatal period.**

*Pr Stéphane Maret, CHU Hôpitaux de Rouen*

Epidemiologic data allow us to say that there is not a single cause for Cerebral Palsy, but an ensemble of risk factors that will act on the brain and the cerebral development, causing eventually Cerebral Palsy. So we must develop neuroprotection and prevention strategies before, during and after birth for children considered vulnerable, or potentially vulnerable in the future. Neonatologists today benefit from a number of tools to move forward in neuroprevention of motor development.

Administered to the pregnant woman presenting a risk of premature birth:

- corticoids, given before birth in case of risk of premature birth, bring a sure benefit regarding lung maturation. They also have a beneficial effect on morbidity and neonatal mortality, and on the prevention of the white matter disease. We do not observe a beneficial impact on Cerebral Palsy at 5 years though, positive effects being counterbalanced with harmful consequences.
- Magnesium sulfate also presents a sure benefit regarding the level of Cerebral Palsy at 2 years. We observe a global reduction of long-term troubles without harmful effects, but the studies lack of power.

Given in the first eight days after birth to prevent the premature child's apnea, caffeine seems to reduce Cerebral Palsy at 2 years significantly.

At last, for the newborn carried to term, hypothermia shows a 24% reduction of Cerebral Palsy at 2 years.

But additional trials must be made to progress in the determination of these treatments' « dosage », which for now is based on clinical observations. And we still have to progress on the clinical description of these children to know what kind of treatment must be administered to each based on

their specific cases. These trials must be integrated in an ensemble of neuroprevention strategies, still to be defined.

*The place of nutritional supplementation (Omega-3) in prevention strategies will be the object of a next Infomotrice letter.*

## **Recognizing, defining and handling chronic pain**

A key research area for La Fondation Motrice



Round table on Pain, March 13th 2015

Moderators: Mr Christian Minet, Dr Isabelle Poirot.

Participants: Dr Catherine Arnaud, Dr Justine Avez-Couturier, Dr Sylvain Brochard, Dr Elisabeth Fournier-Charrière, Mr Philippe Toullet]

### **The words of a father: Christian Minet, President of the AAIMC, Champagne-Ardennes**

I am the father of a young woman of forty, very heavily handicapped and who, like many people with Cerebral Palsy, is suffering a lot. I am very grateful to La Fondation Motrice for working on this very important subject, while listening to the people concerned for whom, I think, pain represents an even greater challenge than handicap.

We must not forget that many of them need to be represented for the simple reason that they are not able to express themselves. Also important: the relations between practitioners and families. Like Dr Cans says: it is not 650000 persons, but 650000 families that are hit by Cerebral Palsy in Europe. Pain is an issue for the patients of course, but also their families, who have to discuss it with practitioners and all caregivers.

### **Physiotherapy-induced pain: what do children think?**

*Dr Sylvain Brochard, member of La Fondation Motrice Scientific Council, CHU Morvan, Brest*

Physiotherapy supports people with Cerebral Palsy all their lives. It is the most frequent therapy. The SPARCLE Study, among others, indicated that this therapy is often painful for children, a point that clinical experience confirms. But how do children live with it?

A qualitative study allowed to collect their personal experiences and to generate avenues for reflection:

- Passive stretching seems to be the first cause of pain in physiotherapy. We should check that, and be extra-careful from now on with stretching exercises
- Is it useful for children to suffer, is the level of evidence enough to go on with painful exercises
- How to maintain the quality of the relationship between the therapist and the child over time
- We should ask questions during consultations to detect pain and adjust accordingly

## **The place of physiotherapy in non-medicinal care**

*Dr Philippe Toullet, Institut Motricité Cérébrale, Paris*

Through manoeuvres of automatic relaxation, and by trying to prevent orthopedic troubles, the first goal of physiotherapy is to prevent pain.

To say that there are care-induced pains indicates that there is a need for formation for professionals, practitioners, but also parents. We should not « fight » pathological postures, but help children to relax, and be careful with all these daily gestures (like pulling arms to slip on clothes) that represent small aggressions. We should not pull in muscles either. We will rather use the muscle's properties, change its state of contraction, propose postures and activities on the new amplitudes, using the global motricity of the child. He is active, there is an interaction with the physiotherapist. We'll speak not of stretching, but outstretching. We lack studies on our practices, but it is very possible that we spend much time inflicting pain, for uncertain results.

Pain creates a vicious circle. The child loses confidence, is in avoidance, and every movement becomes painful.

So I'm in favour of a joyful physiotherapy !

## **Progress in medical imaging**

*Session sponsored by the SESEP*

***Pr Patrick Van Bogaert, Erasmus Hospital, Bruxelles***

The study of white matter tracts (where are located most of the cerebral lesions of the premature child) by certain DTI (Diffusion Tensor Imaging) techniques indicates that « wiring » is settled early in life. Functional DTI, and study of functional connectivity at rest, revealed that specialization in the brain starts early, in the first year of life, with early maturation of the primary areas (sensorimotor, sensitive and visual).

***Dr Mickaël Dinomais, CHU Angers***

Study by functional DTI of the sensorimotor system's reorganization in children who had neonatal CVA proved the link between the structure of the lesion and the becoming of the child's motor functions, and the poor plasticity of the motor system (which allows not to change the motor status, but to gain in efficiency for the walk, for instance). It also indicated that certain forms of reorganizations (ipsilateral, where the healthy cortex takes over from the damaged one) are quite rare after a neonatal CVA.

## **Therapeutic utility of mirror training for the hemiplegic child**

*Dr Christopher Newman, Nestle Hospital CHUV, Lausanne*

Mirror therapy, first used to treat phantom pain of the amputated members, also proved its efficiency in the treatment of the upper member hemiparesis in adults who had a CVA. This therapy consists in placing a mirror between the two arms. The « plegic » arm is hidden behind the mirror, which is turned to the healthy arm in order to see its reflect in the mirror and to have the impression, or the illusion, that the reflect replaces the « plegic » arm.

A controlled randomized study conducted on children, comparing a bimanual symmetrical training with and without illusion of the mirror, concluded to a significant benefit for the strenght, the function and the skill of the paretic member thanks to this bimanual symmetrical mirror training, but it did not prove that the mirror illusion itself had any effect. One can consider the mirror an interesting motivational factor though. This study raises questions about physiological mechanisms at stake in both cases. The comparison with other techniques such as constraint-induced therapy seems

necessary to determine which treatment is more appropriate for which category of hemiparetic children.

*« In addition to classic therapies, we are now developing the use of robots and games in movement therapies. We work on gestures and postures with a tool able to motivate the child, allowing to repeat gestures. It demands an important cooperation between engineers and practitioners. »*

*Dr Huub Van Hedel, University Children's Hospital, Zürich*

More information on [www.lafondationmotrice.org](http://www.lafondationmotrice.org)

## **Elaboration of recommendations for better reeducative pluridisciplinary treatments of Cerebral Palsy. An important stake for the future.**

The concept of « evidence-based medicine (or practices) » gets more and more attention in international learned societies. They emphasize the level of evidence brought by quantitative studies, allowing to determine a risk-benefit ratio to edict good practice recommendations. That's what the European Academy of Childhood Disability started to do, with the elaboration of recommendations in Cerebral Palsy.

This approach raises questions on certain reeducative practices based on experience only, and leads national learned societies, as well as everyone involved in reeducation, to have a methodological reflection on the state of their knowledge, its diffusion and the current practices.

### ***Dr Eric Bérard, member of La Fondation Motrice Scientific Council, FFAIMC***

It is important that families are being consulted during the elaboration of these good practice recommendations. A workgroup will be created to this end, with the elaboration of a survey for families, to determine their priorities in matter of reeducation and collect their opinions on these practices.

### ***Pr Isabelle Desguerres, President of the French Society of Neuropediatrics, Hôpital Necker – Enfants malades, Paris***

We must reinforce the collaboration between all partners, the dialogue between the scientist and the person hit (the one with a theoretical or practical knowledge of the handicap, the one who experiences it), and give ourselves the necessary methodological means to elaborate good practice recommendations.

*« At the end, who is in a situation of handicap when one doesn't understand the other: the « normal » individual or the one who has trouble articulating? Some say: I feel handicapping rather than handicapped. I handicap the others who have trouble understanding me, but I hope this will allow them to start to change their way of thinking ». An adaptation process is always reciprocal. »*

*Pr Pierre Ancet, University of Bourgogne, CNRS, Dijon*

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### **La Fondation Motrice, Research into Cerebral Palsy**

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