Research on pain

Infomotrice





Help us fight pain

Clémence, Adèle and Matthieu told us on the first day: « no one can live a whole life with pain ». Cécile's dad, whilst contemplating his child, lying all day in a molded shell, subject to involuntary contractions, and unable to speak, asked me: how can one respond to this pain?

Since its beginnings, La Fondation Motrice has considered pain to be a major issue, for both children and adults with Cerebral Palsy. Strong and repeated involuntary contractions, emotions or noises that reinforcing such contractions, inappropriate installations, invasive care: there are numerous sources of pain.

The first projects that we were able to fund reminded professionals of this everyday concern for children: what deteriorates their quality of life is pain.

This pain that no one spoke of, as no one knew how to handle it, became a research topic. It led to the training of professionals, as well as group work, at La Fondation Motrice as well as many of its partners.

In order to make progress in the research, bring new knowledge on the subject and offer new solutions, we have mobilized experts, asked for your support and looked for sponsors.

This letter aims to present the research projects that we are funding this year, thanks to your donations, and most particularly the ones from La Fondation CNP-Assurances and the Association TFWA. Sharing the hope brought by this research is our way of thanking you all.

If our volunteers, Nathalie and Lucie, are so sure of their engagement, if researchers trust us, if all of them are only thinking of how they can bring back joy to children, for whom pain remains a daily reality, this is all largely thanks to you, and to your support.

Make a donation now to be a part of our research campaign 2013. We must go further.

THANK you

Alain Chatelin

President

La Fondation Motrice has the great pleasure to announce you the meeting

Pace Approach: Perception, Action, Cognition, Environment

New tools for an integrated and developmental approach of Cerebral Palsy and other complex brain pathologies

Friday, November 29, 2013, Espace Saint-Martin, Paris 3

Research on pain is making progress

The laureates of our call for research projects 2012

For children with Cerebral Palsy, who want to enjoy a social life, pain represents a major obstacle. Favoring research on this area thus represents a priority for La Fondation Motrice.

Why a call for research projects on pain?

Nathalie Genès, practitioner and head of the "Pain" project at La Fondation Motrice:

Often unknown, pain is a permanent reality for persons with Cerebral Palsy, and greatly affects their quality of life. Children are also suffering from it, from an early age, as well as teenagers, for whom it represents, according to a study led by the European network SPARCLE, one of the major obstacles to having a social life.

Improving the handling of pain in children and teenagers with CP is one of La Fondation's top priorities. We thus launched, in august 2012, a call for projects that aim at supporting concrete and innovative initiatives in that area.

Three teams have been chosen by a multidisciplinary committee composed of experts, and now benefit from the financial support of La Fondation Motrice, along with its partners, to achieve their research programs.



Evaluating pain better

Pain evaluation for non-communicating children



Dr Justine Avez-Couturier (Neuropediatry, CHRU Lille)

The regulation process of the cardiovascular system (heartbeats, respiration...) by the autonomous nervous system is closely linked with the perception of pain, and can be measured by analyzing the heart rate variability (HRV). The work accomplished by the CIC-IT 807 laboratory (CHRU Lille) led to the creation of an index based on the heart rate's variations, showing an important sensitivity to painful sensations.

Our purpose is to show that this index, already validated for adults, can be used for children with CP and that it would also be sensitive to pain. This tool could help evaluate pain for children experimenting difficulties in communicating, for instance in the case of Cerebral Palsy, and allow real improvements in matter of handling the pain, with concrete applications like pain monitoring, and possibly the creation of a "smart" bed or wheelchair, adapting itself according to these measurements.

I'm a trained pediatrician, specialized in pediatric neurology. During my internship, I took interest in children with Cerebral Palsy (CP) and have been confronted to very complex and painful situations. The handling of pain thus became a big part of my training.

I was working for my research with the CIC-IT 807 Laboratory, within the CHRU of Lille: one of the research themes was the objective evaluation of pain, particularly for new born babies and children. This is a very innovative topic that should allow not only to recognize pain better in children with CP, but also to improve the technical aids these children are using on a daily basis.

This is a very concrete topic for me, since I regularly meet in my consultations children with CP, along with their families, from the day of the diagnosis. I also particularly appreciate team work and multidisciplinary approaches: this project is a good example, since it teams together practitioners, physiotherapists, nurses, psychologists, engineers, researchers...



Studying the analgesic effect of an anti-osteoporosis treatment



Dr Agnès Linglart (Pediatric Endocrinology, Hôpital Bicêtre, Paris)

Scoliosis is a very usual complication in polyhandicapped children that can lead to spine surgery. Osteoporoses, as well as the associated fractures, are two usual complications of the child's polyhandicap. Bisphosphonates used to treat children's osteoporosis are known to exert an important analgesic effect. The project aims at evaluating the analgesic effect of the bisphosphonates on a postsurgical pain, in the case of spine surgery for polyhandicapped children, including children with Cerebral Palsy.

This multicenter pilot study will analyze, between other things, the length of stay in recovery unit, the duration of the morphine use, and the pain scores recorded while in recovery. It associates the Hospitals Bicêtre, Trousseau and Necker in Paris and Nimes. The results will be used as a base for a controlled prospective experiment evaluating the bisphosphonates' analgesic effects to frame spine surgery.

I am a pediatrician, working in a hospital, and I'm interested in diseases affecting the child's skeleton, particularly in child osteoporosis. In 2002-2003, after having been asked by neuropediatricians along with pediatric surgeons, I focused on radios of polyhandicapped children with femoral fractures, which led me to a couple of conclusions: osteoporosis is an important and painful complication of the child's handicap, and there is a treatment that can be proposed. My colleagues and I thus launched a number of research projects on this subject.

With this treatment, things change. More importantly: this kind of handling aims at preserving and preparing the adult life of these children, a very positive and motivating prospect.



Studying the opportunity of taking analgesics before physiotherapy sessions



Pr Olivier Rémy Néris (PRM, CHRU, Brest)

A number of studies with children and teenagers mention the presence of pain during physiotherapy sessions. Despite the physiotherapists' personal implication, it seems that the pain provoked by their cares isn't sufficiently taken into account yet. This project, led with unusual conditions of care, aims at evaluating the interest (efficiency and tolerance) of an analgesic (ibuprofen) taken before the physiotherapy sessions for children and teenagers with CP. This study, associating six medical centers, consists of a measurement, during rehabilitation sessions, of pain and anxiety levels in children having received either an analgesic treatment, either a placebo, before each session. This study will be the opportunity to make the medical staff more aware of pain evaluation, maybe to make it consider more often this tool during reeducation.

This research project comes from a clinical concern: minimizing pain during technical medical gestures like botulinum toxin injections – something I'm training my youngest collaborators on. One of them developed a great interest in the matter, and we have come to develop a whole set of projects regarding pain prevention, in MPR care.

We first heard of La Fondation Motrice when studying Cerebral Palsy in the frame of our research on pathological movements' biomechanics, our main research topic. We contacted the foundation again while developing more clinical projects in this area; this project on pain is a new occasion to work together.



Heroes' Race 2013

Running for research!

On Sunday, June 16th, La Fondation Motrice will team together runners and walkers at Parc St-Cloud for the Heroes' Race. After the 60000 Euros collected in 2012, the objective this year has been raised to 100000 Euros in order to fund research projects like the ones we are describing in this letter. So go check our page, and help us share the news!

http://coursedesherosparis2013lafondationmotrice.alvarum.net

Like Pierre-Marie, you can join a running team from La Fondation Motrice and collect funds, or simply help us by supporting a team. Thanks to everyone and good race!



"I've been a part of the Heroes' Race for three years. I'm running for La Fondation Motrice because its project is research on Cerebral Palsy, which affects persons with cerebral-motor disability like myself. I'm a member of the Association Les amis de *La Fondation Motrice*, like many of my friends. To collect funds, I wrote a text on my page to explain the race's purpose, the day's program, in which team, and what cause I'm running for, and also what amount one must raise in order to participate. I also sent it to all of my personal and professional network.

I'm running for a cause, but what also motivates me is the pleasure to participate, to have a good time with the other members – if it is like last year, under a blazing sun!"

Pierre-Marie Nicol

An example of research project funded by your donations to La Fondation Motrice, with the support of its partners

Reflection on pain in children and teenagers with Cerebral Palsy, led by a multidisciplinary expert team, brought La Fondation Motrice to support the QUALIDOL project.

This project, led by Pr Olivier Rémy-Néris and Dr Sylvain Brochard (MPR Unit, CHRU Brest) aims at collecting information from children and teenagers regarding their pain, by means of semi-directed interviews.

This study aims at presenting not only the pain's localization, but also its chronology, duration, its aggravating and relieving factors. This work will allow us to describe more precisely the pain's characteristics in children and teenagers, and thus lead us to a better handling.

Almost 3000 Euros in one evening!

March 9, last year, a concert in Trainou (45) for La Fondation Motrice's profit allowed us to collect 2800 Euros. A great big thank you to Lucie's grandmother!



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Registered as a « government-approved and endorsed public foundation » in July 2006 President : Dr Alain CHATELIN – President of the Scientific Council : Pr Marie VIDAILHET

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Founders: APETREIMC (2005), SESEP (2005), CDI (2005), PASSERAILE APETREIMC (2006)

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