

Dear friends,

La Fondation needs your participation and your donations to progress. Being a research institution, we thought we would let Pr. Marie Vidailhet, Chairman of our Scientific Committee, explain our action. We are deeply grateful to the Scientific Committee for their dedication and hard work. The next issue of this newsletter will therefore be totally dedicated to the projects supported by La Fondation in previous years and those selected in 2008, so that you know how your money is used. This issue is dedicated to the child's rehabilitation/education as our mission also covers the quality of care. Please help us by distributing our Newsletter around you. It is very important for all your children.

Thank you all for your help!

Alain Chatelin
President

Dear friends,

La Fondation is young, both in existence and by the age of its members. It thrives on the energy of all those who support its action, the work of its Scientific Committee, the commitment and implication of the Board and its Friends' association. We must deploy this energy but also make strategic choices, choose which projects we want to support, communicate about who we are and what we do to raise awareness among the medical teams, the researchers and the medical public about cerebral palsy pathologies.



From a scientific point of view, we have been able these last few years to give strong support to research projects and with the Scientific Committee's help we shall continue to support projects in this field. We shall also try to attract to La Fondation new research teams, while promoting our own resources, i.e. those top level researchers who already joined us in our efforts. Of course, clinical studies related to care will not be neglected, as it is the indispensable complement of a more fundamental research. We shall revert to this later in this Newsletter.

Furthermore, an important step is also to be known and to clarify our message (or even simplify it). We need to make clear the pathology diversity as well as its identity and its singularity. Dr. Daniel Ejnes, Project Manager, and the operational team help us determine an approach for the future in this field.

I wish to thank all those who have contributed in recent years to make these projects a reality.

I am very grateful, in particular, to Prof. Louis Vallée, my predecessor, for his leadership and vision; to Dr. Lucie Hertz-Pannier, for her energy and her talent to organize and implement projects and meetings; and, finally, to Dr. Alain Chatelin, President of La Fondation, for his strength, conviction, energy and his capacity to analyze and communicate his enthusiasm to help us implement our projects.

Professor Marie VIDAILHET
Chairman, Scientific Committee

CHILDREN'S REHABILITATION

To most of us, the word “research” evokes fundamental research, laboratories and white coats... However, research and particularly in the field of cerebral palsy, includes very diverse fields of action, some of which lead to short term applications: for instance, in relation with clinical examination and rehabilitation.

Let's review the situation with Michel Le Métayer, CDI Chairman and member of the Scientific Committee of La Fondation.



What are the priorities in relation with rehabilitation today?

The most important thing is to advance in the field of clinical examination and rehabilitation techniques, that is in what should be called therapeutic education. These two aspects are indeed complementary : techniques are chosen according to each subject's specific problems, knowing that cerebral palsy problems are not the same in every child. On the other hand, using these educational and therapeutic techniques requires to be aware of their pertinence, through a research and evaluation approach.

Concerning clinical evaluation, we have at your disposal since several decades qualitative and quantitative scales that deserve to be better known. Some of the most recent ones call for a new validation and statistical studies approach, which is another aspect of research. As it is not a research conducted in laboratories, it should be said that clinical examination, in professional practice, is done with measurement methods that use the eyes, the hands and some simple instruments to measure the angles for example. In simple terms, the approach is as follows:

1. Identify each existing problem using a defined technique (qualitative evaluation).
2. Measure the importance of each problem (quantitative evaluation).
3. Understand their functional effects and possible interactions with other types of problems, then evaluation the resulting handicap (functional quantitative evaluation).

Thus, after medical treatment and/or a period of therapeutic education, it is possible through examination to measure the functional benefit, evaluate a quantitative reduction of the problem and observe it temporary or definitive elimination.

Also, if the problem has been precisely identified, the role of laboratory research is to give a physiological and pathological explanation and promote a better understanding of therapeutic and rehabilitation practices.

One can see from this global view the main fields of research directly related to therapeutic education and rehabilitation of children suffering from cerebral palsy.

In this very wide field what are the projects you are particularly interested in?

There are several kinds:

- First of all, give clinicians research training: it is very important. Today, rehabilitators do not have sufficient information concerning the preparation and execution of a clinical research project. Even though many of them know the evaluation tools, they do not use them systematically with research in mind. It is not sufficient to inform, it is also necessary to organize training programs and help those who like to further their knowledge, have a fertile imagination and dare question the traditions.
- To progress in clinical evaluation of motricity (MOTRICITE) by using electromyography not only for walking capacity evaluation, which requires technical installations that are costly in time and money. Today, it is possible to get good quality but less expensive equipment, but also to learn how to obtain reliable signals and interpret them. Thanks to electromyography, it is possible to detect with great accuracy gestural execution problems during examination and to measure their mitigation as the subject is treated and according to the techniques used during the treatment.
- To improve our knowledge of automatic and innate motricity, that is go further voluntary motricity, which is not sufficient to organize LES REDRESSEMENTS, LES DEPLACEMENTS and all series of movements necessary in everyday life. Indeed, newly born babies have prefunctional motricity represented in particular by antigravitation automatisms (AUTOMATISME ANTIGRAVITAIRES) that are necessary to counterbalance the EFFETS DE LA PESANTEUR and develop balance. These programmed functions do not disappear when the baby grows older but become less obvious to the observer when voluntary motricity (MOTRICITE VOLONTAIRE) comes into play. Some studies have been conducted during the last 25 years: they need to be implemented among large populations of children, both valid and suffering from cerebral palsy. Pursuing these studies would bring progress on diagnostic and early evaluation of motricity problems by giving indications as to the individual's future functional possibilities and would prevent false hopes and useless "battles". The challenge is all the more important that therapeutic education techniques are being developed in relation with that innate CEREBROMOTRICE potential for many acquired movements, like sitting or walking. Knowing these automatisms also permit rehabilitators to reveal automatic muscular contractions, when requesting voluntary movements by traditional methods brings no result. Therapeutic education of TROUBLES DE LA MOTRICITE BUCCO-FACIALE follows the same principles to elaborate specific learning techniques for feeding and phonation (PHONATION).
- To codify automatic relaxation techniques empirically discovered and study their modalities and effects resulting from electromyography. This should be done if we hope to find the neurophysiological explanation to effects provoked by appropriate manipulations. These physical manipulations have been taught for many years to learn how to manipulate comfortably cerebral palsy sufferers or polyhandicaped individuals in daily life, guide them in rehabilitation activities and assist them during clinical examination.
- To improve treatments to prevent and cure orthopedic problems. To evaluate better clinical situations that present threats of possible orthopedic disorders to organize prevention. For instance, it is possible today to improve prevention of hip dislocation, thanks to specific installations that do not prevent children to change position during the day and to appropriate exercises executed with educators. In these conditions, a minor surgical operation can be done as soon

as it appears that rehabilitation is not sufficient, preventing thus heavier operations on the hips in the future.

- Finally, we can improve therapeutic education and rehabilitation practices where pedagogy has not always followed the development of our knowledge in neurosciences. We must nevertheless work on the way to improve learnings and their automation, by adapting the duration and frequency of repetitions. We need to avoid what is called “habituation” as it does not permit any significant modification of synaptic activity (ACTIVITE SYNAPTIQUE) nor verifiable neurobiological modification.
- I will not say much about past testing destined to try and improve movement control by means of vibrating devices that produced illusions of movement by amplification of the movement: these tests have been suspended for lack of financial resources.

There are many other themes, of course. We have not finished discovering all there is to know about cerebral palsy and it very important that doctors and rehabilitators study these subjects, be helped in their investigations and that the word “research” be “demystified” in the eyes of some rehabilitators.

FOCUS – Valérie Achache is a physiotherapist. She has been working since 1992 with children presenting cerebral palsy disorders in the Rehabilitation Center for Congenital Neurological Pathologies, Hôpital national de Saint-Maurice. She also participates in research projects supported by La Fondation.



The first step, when working with children suffering from cerebral palsy is to evaluate their motor capacity (CAPACITE MOTRICE) by observing different factors likely to have an effect on motricity (MOTRICITE) integrity. The next step is the implementation of a rehabilitation program corresponding to their needs. The program includes several aspects :

- orthopedic maintenance, with manual stretching using relaxation manipulations and installation of postures (ORTHESES, CORSET-SIEGE, POSTURE DE NUIT ...) ;
- global neuromotor guidance through an evolution level matrix (“NIVEAUX D’EVOLUTION MATRICE”) that allows to do specific exercises such as TRANSFERT D’APPUI and postural adaptation, straightening work, coordination, etc. ;
- awareness and enhancing of more selective motor activities (ACTIVITES MOTRICES) as RELEVEURS DU PIED reinforcement, for instance ;
- transferring what has been learned in functional situations of everyday life (for instance, taking up and down a manual wheelchair) ;
- installation of technical aids (rollator, customized tricycle ...).

In recent years, new evaluation (Quantified Analysis of Movement) and therapeutic (functional electrical stimulation) tools, resulting from technological breakthrough, have been adopted to treat children. They are part of the child’s global project within

a multidisciplinary team and in coordination with the family : we thus guide the child throughout his development.

Sixteen years spent with children suffering from cerebral palsy have raised many questions, some of which remain unanswered. This situation led me to conduct some research, with the financial support of scholarship granted by La Fondation Motrice. I worked with the U731 laboratory of INSERM-UPMC at La Pitié Salpêtrière hospital, a specialized unit working on RESEAUX NEURONAUX SPINAUX related to motricity (MOTRICITE). The dysfunction of some of these RESEAUX could be a cause to motricity disorders in cerebral palsy. A better understanding of the way they function could help adapt specific therapeutic tools. I find it important to maintain a link between my practice and research, as it leads to a questioning process likely to help find appropriate answers to the needs of individuals suffering from cerebral palsy.

HOW DO THE PARENTS LIVE THEIR CHILD'S REHABILITATION?

Florence, mother of Coralie (10)

“The most important thing for rehabilitation to be successful is to create a close partnership between the rehabilitators and the parents. When rehabilitators make the effort to **share** and **explain clearly** what must be done, parents do react positively and a **common dynamics** is created between what is done at home and what is done during the rehabilitation sessions.

At the beginning, when the child is very young, the parents dream that rehabilitation will “save” him. But reality hits us, professionals use rehabilitation to explain what our child will be able to do and his limitations. We trust those who know how to explain what they do, why and how they do it and above all who have the same **ambition** that we have for our child. For instance, when our daughter was 4 years old, our priority was that she could walk normally. When rehabilitators explained to us that she would not be able to reach this stage without first being able to walk on all fours, it was easier for us to accept that they continue working on this aspect of the program.

If there is no sharing of knowledge and information, everything comes to a stand still and it is impossible to progress. It is absolutely necessary to avoid this type of situation, as is it difficult enough already, particularly when one no longer understands the direction nor the priorities of all the work. This is when rehabilitators must **adapt** and continue working while helping us to avoid mental exhaustion. What also makes a difference is their capacity to explain the **challenges of rehabilitation to the children** and then adjust **learning to their motivation**. Rehabilitation is crucial for our children and adults must find solutions to make them accept and bear their sessions. In fine, it could be said that **rehabilitation is a game of creativity in learning situations**”.

Practically, how is built a rehabilitation program for a child? We asked Carole Bérard, Director of l'Escale, Pediatric Rehabilitation Unit, Centre Hospitalier Lyon Sud, and a member of La Fondation Motrice Scientific Committee.



Before mentioning children's rehabilitation, let's say that this term comes from what is done with adult patients but when children are concerned, it is rather a question of education. Rehabilitation implies physiotherapists, ergotherapists, rehabilitation and speech specialists and PSYCHOMOTRICIENS. It also has a wide application in all aspects of the child's life.

The first thing that determines what will be done is the child's health condition. Whether he or she is able to cooperate is then taken into consideration: his/her understanding of the objectives, his/her capacity to give an opinion and his/her behavioral specificity (for instance, acceptance of physical contact is crucial). Finally, what the parents expect from the professionals and their trust is also very important. Some accept the medical team's project and trust it. Others will want to be more closely implicated and to control what is done to their child: those will find it more difficult to work within the teams. Others will try to find solutions in alternative medicine or in other countries. These three approaches are to be respected and will determine rehabilitation.

Considering all these factors, we define rehabilitation goals and priorities which can vary from time to time. They relate first MOTRICITY, then language and communication and finally everyday autonomy. The next step is how to reach these goals determined: the professionals determine what is possible and desirable for the child and the parents decide what will be done. Therefore, there is an exchange between parents and medical teams, and permanent adjustments depending on how the child's condition evolves. As a summary, it can be said that a rehabilitation program is a compromise between what is possible, desirable and



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If you wish to make your donation by monthly standing order, please contact us.

La Fondation Motrice is recognised as a government approved charity ("*Fondation reconnue d'utilité publique*"): with respect to French legislation your donation gives you the right to an income tax reduction of 66% of the amount of your donation. Thus, a €100 donation will cost you €34 if you are liable for tax.

If you are paying taxes outside France consider local legislation.

At the occasion of this donation, I wish to become a member of the Friends of the Fondation Motrice

☐ yes ☐ no

THEY SUPPORT US

More than 110 000 euros were raised for research on cerebral palsy at a charity diner organized by Andrea Casiraghi, sponsor to La Fondation Motrice on June 17th, at Maxim's.



Many celebrities were present, including HRH Prince and Princess of Hanover and the diner was largely commented in the international press, thus contributing to bring to light both La Fondation Motrice and the cause of cerebral palsy.

We wish to thank Andrea and his friends, Pierre Cardin and Maxim's and all donors.



3 QUESTIONS TO Jean Lucas, President, ADIMC Côtes d'Armor.

ADIMC 22 was created in 1987 to examine and promote any project in favor of cerebral palsy sufferers in the region. In particular, ADIMC operates Ker Spi, a hostel with medical assistance inaugurated in 1992 in Plérin and helps 35 adults with suffering from CP or polyhandicapped (at the hostel, in specially adapted houses or flats).

1. What are your association's missions?

The well-being of CP sufferers can be promoted in various manners. Our first goal is to facilitate their school, social and cultural integration, to listen to parents and offer them logistics means and experience and to anticipate our aging populations' evolution. Therefore, we interact with the authorities to create appropriate structures as we do not have enough of them in our region today. But we also think very important to inform about CP, its particularities and the needs of those who suffer from it.

2. Why do you support La Fondation Motrice?

We have supported La Fondation from its inception as it bring enormous hope to sufferers from CP and their family and as it is not as well known as it should be ! Cerebral palsy is not a well know condition and the mere existence of La Fondation is crucial. We therefore contribute financially and we distribute the Newsletters with our own mailings: it is an important tool.

3. How to raise awareness to the fact that you represent the cause of research on cerebral palsy?

We want to implicate families as much as possible: this is the reason why our strategic orientations for 2008/2011 have been determined in association with their help. We have 11 development projects each of which will be managed by a team of three individuals : one patient, one administrator and one professional. Locally, we try to create as many contacts as possible with the press or elected representatives in particular taking advantage of special occasions like exhibitions, shows, etc. that take place in our hostel. But it is a fact that cerebral palsy still lacks visibility and communication at the national level. May be, like other associations have done, we could increase the notoriety of our cause through participation in TV programs or games. The public needs to be informed about the reality and all aspects of cerebral palsy and we must raise funds to finance research.

Spread the letter of La Fondation Motrice around you. It is available on the web site www.lafondationmotrice.org

MERCI À **Sabine Chabbert**, Director of Beyond Beauty Mag, who raised some 1 300 euros to be donated to La Fondation Motrice, by organizing a sale of beauty products and cosmetics at a "Perfumery Diner" on the 8th of April.

NEWS

AGENDA

Our next seminar will take place March 7, 2009 at Institut Pasteur in Paris.

More information in the next issues

Call for research projects 2008

Thirty nine projects have been submitted to La Fondation Motrice for France (Inserm, CNRS, universities and hospitals, INRA...), Germany, Australia, USA, Great Britain, Italy and Switzerland. The Scientific Committee held a reunion on June 30th and the results will be presented in the next issue.

Welcome to Marie Roinet, Manager, La Fondation Motrice

In charge of communication and fund raising, her main functions are to increase the notoriety of La Fondation and awareness of its action, to search for long term sponsoring programs and to set up a network in support of CP.



- **Future approach for research on cerebral palsy, with the support of CNSA :** un workshop on pain took place in July, others are scheduled about communication and language, CP and wheelchair, CP and cognitive disorders. Results will be published in the 4th trimester.
- **“What does it mean to accompany a handicapped person ?”** Such was the theme of a seminar organized par I=MC² in Chessy on May 13 and 14. A White Paper will be published later. During the seminar, Patrick Gohet, in charge of handicapped persons in the French government, declared that a national task force on CP will be set up in june 2008 and its mission will be to inform on this handicap to allow for a better response to the needs of sufferers.
- **Annual one day meetings of CDI : December 12 & 13, 2008, Maison de l’UNESCO :** “Children or teenagers with CP : transition to adulthood” : The IMC training sessions program has been established. See www.institutmc.org.
- **La Fondation Motrice will participate in the celebration of APETREIMC 30th anniversary on November 30, 2008.** Contact : Apetreimc 01 45 54 29 99

Book – *La paralysie cérébrale de l’enfant – Guide de la consultation – Examen neuro-orthopédique du tronc et des membres inférieurs* – par Carole Bérard, with a DVD, Edition Sauramps Médical, 265 pages – 50 euros.

Andrea Casiraghi visiting a Rehabilitation Center for very young children run by Dr. Jeanne-Charlotte Carlier, General Manager of SESEP, founding member of La Fondation Motrice.



Andrea Casiraghi with Dr. Pierre Gressens in his laboratory of Hôpital Robert Debré in Paris, Several researchers of this hospital received scholarship from La Fondation Motrice to conduct studies on protecting the new born's brain.

