

« If nothing is done for us then I will never be able to walk ? »



How can we face Guillaume, whose words express his distress, if we do not try everything ? How can we answer him if we do not commit ourselves with all our energy ?

Dear friends,

We created La Fondation Motrice with those words in our heart.

It is also one of the first things that parents who come to consult with their baby ask : « **Will our child be able to walk ?** ».

Your donations allowed us to finance several research projects currently under way. Dr. Carole Bérard, member of our Scientific Council and Head of Department at l'Escale hospital in Lyon, explains in this letter all that has already been accomplished and what remains to be done: **preventing brain damage** at birth, bone and muscle **surgery**, injection of products to temporarily block abnormal muscle spasm, **walk analysis** through video, training on rehabilitation progress, etc.

For those who do not walk, becoming autonomy requires **technological innovations**; for instance, **intelligent wheelchairs** to help them find their way, climb stairs or relieve muscle pains through micro-movements.

Yann Le Lay, physiotherapist and trainer, explains what precision is needed when taking charge of a newborn, as **everything is decided during the first years**: walking and teaching children who cannot walk **to enjoy moving** and acquire an autonomous mobility that will allow them to discover the world.

Families are aware of all the benefits their child enjoys when he or she joins a kindergarden with a **multidisciplinary team with a specific CP training**. But it remains to be demonstrated, based on scientific studies on prevention of orthopaedic complications as well as on cognitive and motor development, to convince authorities of the necessity to support this type of structures.

Valerie Achache, doctor in biology, explains that thanks to a grant from La Fondation she has been able to spend 4 years to do research in a prestigious laboratory at La Salpêtrière hospital in Paris to reach a better understanding of **motor trouble mechanisms**. A deeper knowledge of such problems may produce new ways of rehabilitating and treating patients.

La Fondation Motrice is active on several fronts. Thanks to your donations, thanks to events like La Course des Héros (Heroes' Race), we have made progress.

But this year we have not been able to finance several projects: like many associations, we are faced with a reduction in resources and we had to give up or put on hold various projects.

High hopes are placed on La Fondation. Will you help us realize them?

We are at year end and it is urgent that we keep our promises. Please, be generous as your donations finance those progress that Guillaume and his/her friends dream about !

Thank you very much.
Dr. Alain Chatelin
President

*Cerebral palsy affects one out of 450 newborn babies.
In France, 125 000 persons, children and adults, are suffering from CP.
Premature birth is one of the main causes of CP
It can happen to anybody!*

THE LONG WAY TOWARDS WALKING AND AUTONOMY

The parent's first concern when told of the handicap ("will my child be able to walk"), walking is among the complex issues of CP.

Carers and researchers focus their effort.

→ Can we hope to see more children with CP walking one day ?

A review of the situation with Dr. Carole Bérard, Head of Department at l'Escale, Centre for paediatric rehabilitation, hospital for women and children in Lyon and member of La Fondation Motrice Scientific Committee.



Yes, we have reasons to expect some progress as far as walking is concerned. Before we talk about our hopes, we must keep in mind some data to better understand our approach and the problems we face:

- Not all children will walk. Cerebral palsy is an incurable and the children we help today are those who are less affected.
- The capacity to walk depends first of all on the nature and severity of brain damages, even if other factors are involved, such as family environment and rehabilitation. We see, in particular, that the more severe the brain damage, the sooner the child will reach its maximum in motor capacities.
- Walking is not always definitive: muscles contractions that hamper motricity become more severe when the child gets older and in particular when he/she reaches puberty. It happens that children who could walk sometimes loose this capacity at this stage.
- Even if we do not always know how to act on the orders the brain sends to muscles, we have ways to act on certain factors involved in walking, in particular :
 - muscle tone, through **botulic toxin** injections,
 - muscle strength and muscle and tendon contractions, through **rehabilitation, splints, corrective bracing and plaster,**
 - bone and joint deformity, through orthopaedic surgery,
- Walking is a complex issue : every child being specific, it is very difficult to generalize therapeutic indications. Therefore, it is particularly important to be able to call on teams with an experience in this field and working in "walking" laboratories (cf. below).



Important headways have been accomplished in the last decades. 40 years ago, children wore painful and often harmful bracing. Some were separated from their family and sent away to follow a rehabilitation program and learn to walk at all cost. Today, new tools are available:

- **Analysis of movement and quantified analysis of gait laboratories** provide a better understanding of walking mechanism and of abnormalities in CP children.
- The use of **botulic toxin** to improve muscle tone and block muscle contractions help reduce bone and joint deformities and protect walking capacities.
- And for a few years now, we have international, quantified and validated scales **to evaluate motor capacities** of CP children. We can now rely on objective data to follow the children's development, the effect of therapies and make a more precise prognosis on the basis of homogenous groups of patients, even if each child has his/her own history.

The next few years should bring more progress in this field. It is therefore vital to invest in **sharing our knowledge** and **training** physiotherapists and nursing teams. In the meantime, it is also important to think in terms of individual autonomy: the main goal, more than trying to walk at all cost, an approach that can sometimes lead to pain when reaching adulthood, is to improve the quality of life for people with CP, their autonomy to move around and their involvement in social life.

THE LONG WAY TOWARDS WALKING AND AUTONOMY

For a better understanding a motor disorders

Valérie Achache, Doctor at UPMC University – Paris 6 who received a grant from La Fondation Motrice describes her research



The subject of my thesis was the **nervous mechanisms that induce muscular rigidity** in young adults with CP. Some of these mechanisms are implicated in **spacidity** (uncontrolled increase of muscle tone), others in the presence of inappropriate spasms appearing during a movement that prevent its correct execution either when trying to execute it or during locomotion.

When studying these nervous mechanisms, we established that **knowing them is indispensable to understand motor disorders associated with cerebral palsy.**

Some can facilitate walking

For instance, among these mechanisms, one increases the quadriceps contraction when putting the foot on the floor, an important phase in walking during which the body weight is transferred on this member. In particular, that increased contraction plays a role in knee stability.

Other mechanisms, on the contrary, impede motor functions

Previous studies had highlighted the link between motor deficit and a dysfunction in some under-used nervous connections that produces a modification of such connections (synapses) between sensitive fibres and certain motor neurones situated in the spinal cord.

Such adaptation would entail an excessive response of these neurones to the sensitive information they receive and would contribute to the muscular rigidity shown by patients. On the contrary, when that synapse functions well it helps maintain muscular tone at a lower level than the level existing in the patients.

This result opens a path for rehabilitation: training and stimulation of these nervous mechanisms by specific rehabilitation techniques could reduce spacidity and reinforce motor control.



How to give maximum chances to the little one?

Yann Le Lay, physiotherapist at CAMSP in Nantes, answers



For parents, walking is a strong, very symbolic expectation

Walking is indeed proof that the child is no longer in its infancy ; it symbolises his/her entry in social life and every parent dreams of walking with his/her child.

The physio and therapeutic team in charge of the child must accompany that dream but also make parents aware of their child's motor potential and limits through objective assessments of his/her motor capacities.

Guiding the child towards autonomy requires his/her implication in a development process

Not all children with CP will be able to walk. Our role is therefore to help them learn how to move, which does not necessarily mean walking, to become autonomous.

With therapeutic training, the child will discover and develop his/her capacities, under the guidance of a physio, in a process consisting of several steps the first of which is sitting, then crawling or moving on all four. At the end of this process, some children will be able to walk, others will have acquired the means to better use their wheelchair.

Physiotherapists must identify the child's limitations with the greatest precision possible, then share this information with the family and therapeutic teams. With the parents, it is important not to focus on walking alone, but to highlight the child's movement capacities that should be nurtured and developed.

Three kinds of challenges for rehabilitation

First of all, the child must apprehend movement, whatever his/her limitations, and moving and sensate experience must be a source of pleasure as well as a source of development.

Then, we must work to develop the child's movement efficiency and muscle strength through games and activities to help him find the right gestures to facilitate his/her moving.

Finally, we try and facilitate harmonious body development and preserve his/her future by preventing bone deformations et limitations to muscle elasticity.

Physiotherapists and trainers must therefore keep in mind the child's specific needs resulting from CP when playing or training. To guide the child towards autonomy, exchanges and complementarities between the various professional is therefore essential. This is how the research projects supported by La Fondation Motrice are incorporated in everyday work with CP children.

LIKE THEM, RUN FOR THE CHILDREN !



The Heroes' Race that will take place on June 26th, 2011 is the perfect opportunity to show your support for research on cerebral palsy.



Ludivine, his mum, and Christian, his grandfather, will run for Matteo !

My little Matteo was born on July 12, 2009 after a ruptured uterus. So it is for him that I will run the race and for all the children and parents affected by cerebral palsy.

Matteo is lucky to have a grandfather who is looking for every opportunity to do something and implicate our family ; it is was his idea to participate in the Heroes' Race. On the 26 of June we shall run together and our "effort" on that day will be nothing compared to what children like Matteo have to do everyday just to acquire a little autonomy.

To collect donations, before the race, we mobilize our family, our friends, our friends on Facebook and we ask those around us to speak about the race including at work : why could we not be supported by a company ?

I think it is easier to mobilize people when they are able to put a story, a name and a face on a cause.

To support Ludivine and Christian : <http://2011.coursedesheros.fr/lesamisdematteo>



Arnaud will run for Tifenn

I participate in the Heroes' Race because my little daughter, Tifenn, 2 and half years old, suffers from hemiparesis (loss of muscle strength on one half of her body) caused by a stroke during pregnancy.

Her mum participated in the race last year and this year it is my turn to launch the donation campaign ! For now, I send call for donations to my friends via the Internet but later on I shall intensify my campaign by contacting them individually.

To support Arnaud : : <http://2011.coursedesheros.fr/tifenn>

➔ THEY RAN FOR LA FONDATION MOTRICE IN 2010 !

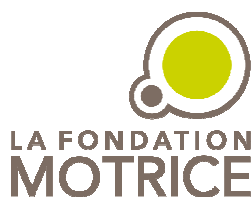
A thousand thanks to our Heroes who participated in the first Heroes' Race in June 2010 and collected 5 066 € in favour of La Fondation Motrice !



Florian has decided to run for La Fondation Motrice

I heard about the Heroes' Race through my mother in law who participated in last year edition. I am a regular jogger and I think that running for La Fondation Motrice was a good idea as I am susceptible to its message : I have reached the age when I could start a family and I am aware that one of these CP children could be mine. To collect funds, I mention the race on my Facebook page and in my email signature. I can thus reach my friends as well as my professional, social and political network.

To support Florian : : <http://2011.coursedesheros.fr/florianchambolle>



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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
Patron : Mr Andrea CASIRAGHI
Founders : APETREIMC (2005), SESEP (2005), CDI (2005), PASSERAILE APETREIMC (2006)

La Fondation Motrice
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SUPPORT RESEARCH ON CEREBRAL PALSY, FIRST MOTOR HANDICAP IN INFANCY



Dear Madam, Dear Sir,

Cerebral palsy (motor function disorder – multiple handicaps) concerns 125 000 individuals in France and one out of 450 new born may be affected.

La Fondation Motrice is committed to prevent this pathology and to do everything possible so that the results of research help improve the quality of life of thousands of children and adults whose suffering is ignored.

We can make a difference !

From prevention to care at all levels of CP, considerable progress is possible. To make them a reality, we need your generosity.

I thank you in advance for your support.

Dr. Alain Chatelin
President

SUPPORT FORM

YES, I wish to support La Fondation Motrice to help it fund research on cerebral palsy (motor function disorder and multiple handicaps), first motor handicap in infancy.

Therefore I donate to La Fondation Motrice :

- | | | |
|---|--------------------------------------|---------------------------------|
| <input type="radio"/> 25 euros | <input type="radio"/> 50 euros | <input type="radio"/> 100 euros |
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| <input type="radio"/> I pay by direct debit | | |

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You will receive a tax receipt for the amount of your donation. Unless you do not wish so, your donation makes you a member of the Friends of La Fondation association.