

The Rehabilitation Charter

The 3 October 2019 was a major breakthrough for the way in which we take into account the expectations of people with disabilities, thanks to the Rehabilitation Charter for people with cerebral palsy, which the government and learned societies committed to as well as representatives for professionals, families and patients.

A charter resulting from the national ESPaCe Study on rehabilitation

The rehabilitation charter for people with cerebral palsy results from reflections organized and collated by the foundation, with the national stakeholders of the ESPaCe study: learned societies, family associations, health professionals and patients.

The ESPaCe study, or Cerebral Palsy Satisfaction Survey, launched in 2016, aimed to assess the current state of motor rehabilitation in France and to determine priorities in terms of improving practices. This national survey with the persons concerned stressed the need for improvements in the therapist-patient relationship, to ensure patients are active decision makers during rehabilitation, and to increase their participation in the setting of objectives. This report generated the idea of bringing together all actors of motor rehabilitation through a strong commitment on shared values.

This charter follows the UN Convention on the rights of persons with disabilities signed in 2006, which was ratified by France in 2007. It builds on the « Romain Jacob » Charter of 2014 regarding access to care for the disabled people.

This charter includes 10 articles that materialize the signatories' mutual commitment. A copy of the Charter is enclosed.

One of the signatories of the Charter representing the French government, Sophie Cluzel, Secretary of State to the Prime Minister and in charge of people with disabilities, stated that this Charter « will lay the foundation for open dialogue so that rehabilitation can be above all at the service of the individual's project, with a shared objective of participation ».

Associations, health professionals, institutions and social welfare groups, in signing this charter, also committed to its implementation.

The Charter is intended to be displayed in all medical, paramedical and medical and social structures, to be an instrument of dialogue between therapists and patients.

The Charter sets agreed standards of behaviour for the improvement in rehabilitation for people with cerebral palsy.


Its aim is to create a drive and to mobilize all rehabilitation professionals such that:

- people cared for gain autonomy and express their needs;
- rehabilitation practices can be coordinated. This should lead to a shared culture between rehabilitation professionals through information and training that take into account the specificities of the disease.

This Charter is thus a guideline for the patient-therapist relationship, a tool for dialogue and awareness as much as a guide to help us with decisions to come.



Dr Alain Chatelin, president of La Fondation Paralysie Cérébrale
Sophie Cluzel, Secretary of State in charge of people with disabilities
and Jacky Vagnoni, president of the FFAIMC
October 3rd, 2019



The rehabilitation charter for people with cerebral palsy

This charter follows the UN Convention on the rights of persons with disabilities (dated 2006, ratified by France in 2007). It builds on the « Romain Jacob » Charter for access to care for the handicapped (2014).

People with cerebral palsy, along with their parents if they are under 18 and/or with a trusted third party if they are unable to express themselves, have the following rights:

- access to rehabilitation whatever their capacity, age or location;
- information on care adapted to their needs;
- respect for their person, intimacy, as well as their own knowledge and choices;
- dialogue with therapists and practitioners to define their rehabilitation objectives, centered on welfare and social participation. Objectives are specific, measurable, achievable and regularly revised;
- adaptation of the rehabilitation timing according to their needs. It may be necessary to choose periods of interruption.

Professionals responsible for rehabilitation acknowledge the above rights and, in the frame of this global therapeutic project, commit to:

- adapting professional practices in line with the specificities of cerebral palsy by building on good practices and current research data;
- taking into account the patient's life (family, school and professional life) in order to define their objectives as well as the timing and methods of the rehabilitation;
- coordinating with other professionals, practitioners and therapists involved with the patient;
- evaluating, preventing and reducing pain due to care in agreement with patients and practitioners;
- encouraging physical and leisure activities.

First signatories of the charter on October 3rd 2019 at Cité Universitaire (Paris)



Sign the charter online

The charter can be signed by all persons feeling affected or willing to show solidarity: rehabilitation professionals, practitioners, patients, families, friends, public organisations etc.

It can be downloaded on our website, for sharing or printing and displaying.

Join the movement!

Information and signature online: www.fondationparalysiecerebrale.org

An important step to go even further



Pr Isabelle Laffont,
president of the SOFMER (French Society of Physical
and Rehabilitation Medicine)

This rehabilitation charter is very important in many respects.

First, it formalizes the need to better organize care for cerebral palsy: reducing territorial inequalities, avoiding interruptions in care, particularly between childhood and adulthood, when patients leave a well-organized system. This charter acknowledges the fact that adults also need rehabilitation and it is very important. The charter's first sentence, which demands access to rehabilitation whatever the person's capacities, age and location is an important tool to move the system and adapt it to the patients' needs.

To many PRM practitioners involved in care, this statement will seem obvious. But the fact that patients felt the need to have it written down shows how much they need to be considered like actors of their own care; like the adults they are. It is a reality that we have to respect, and which requires the social skills of the professionals. It is a fair and legitimate message, shared by patient associations.

On a daily basis, we can see the charter as an educational tool; when practitioners put it up in waiting rooms, it is an implicit way to sort things out and to questions things.

Finally, from our point of view, this charter is a first step towards the next step, which is no less crucial: implementation of good practice recommendations with the High Authority of Health. The charter, which the nation committed to through the voice of the Secretary of State in charge of people with disabilities, will allow us to ask for the necessary means to implement the HAH's recommendations. It will support our discussions with public authorities like Social Security when we will have to define a frame based on these recommendations.

This charter was thus welcomed by the PRM practitioners and the SOFMER, which I represent.



Account: Stéphanie Fauré, patient
A big step towards better practices!

The foundation had already launched a movement with the ESPaCe Study, which highlighted the reality of rehabilitation practices.

To me, the signature of the charter is a new step; it represents a commitment from professionals, who acknowledge the rights of people with CP. For these rights to be respected, concretely, I think that therapists will have to change their approach!

The charter itself should be the source of reinvented rehabilitation. Professionals now have the responsibility for implementing a new balance between constraints and patients' needs to give meaning to their practice. It will result in improved coherence in the way they work, and probably renewed joy in caring, I think we will all benefit from it. We are all looking forward to it!



Account: Valentin Bazire,
father of Gaspard, 4

We acknowledge the charter has many positive aspects, the first one being its clarity.

It also bears hope: we hope that its signature will lead to better listening from the professionals who are willing to commit.

For parents, it is reassuring to know that their child is in the hands of a professional who signed the charter: it means not only that they are listening, but also that their training integrated new techniques and practices.

When we use the word « listening », it is at many levels. There is for instance the question of pain. Gaspard used to work with a therapist who manipulated him without discussing it when in fact he didn't like to be touched. Massages were painful for him. His new therapist takes that into account and includes us in the session by making us read a story at this moment to distract his attention and reinforce his trust.

Dialogue and trust are the key to good rehabilitation. We saw the difference between practitioners, and when the therapist pays attention to the parents' remarks, to the child's tiredness and to the context of the moment, this exchange and the climate of trust lead to more rapid progress.

Likewise, when the therapist makes a movement without explaining it, the child can freeze. If the parents are well informed, they can continue to explain. It also means that the therapist uses terms that are not too technical, that parents can understand.

Gaspard is only 4, but thanks to this exchange, he already understood that if he « plays » well during these sessions, it will be beneficial for him later. This tripartite trust leads to more serenity and quicker work.

Listening also means taking into account the parents' family and professional lives, as well as the child's school life. This understanding is crucial to make things right.

We don't know if the charter will solve everything, as we also expect better coordination between all professionals: coordinated care allows to detect gaps, to better understand children's needs and thus to facilitate care.

« The rehabilitation charter is in line with the approach initiated by ergotherapists »



Nicolas Biard, technical manager of the ANFE*

We contacted the foundation as soon as the ESPaCe study's results were published: the study shows that families demand better access to ergotherapy, which is consistent with our fight to make our discipline more accessible to those who need it. One must know that today, ergotherapy is not subsidized, which means it is paid in full by families when the person is not followed in a specialized institution like a SESSAD.

On that point, demands from professionals, patients and their families meet.

So we naturally associated ourselves with the rehabilitation charter, since this approach is in line with the work we initiated five years ago and which will be achieved at the end of the year.

We elaborated professional rules for ergotherapists that will be voted on at our next general meeting on 23 November before they are submitted to the Ministry of Health for release of the implementation decree. From this moment onwards, our good practice rules will be enforceable.

In that, we share the values conveyed by the rehabilitation charter: we care about setting in stone the professional practices that provide the best care for patients.

We thus welcome this approach, with which we are very happy to be associated.

* French National Association of Ergotherapists

« This charter is a tool, it demands means »



Pascale Mathieu, president of the French national board
of masso-kinesitherapists

This charter is important since it specifies the rights of patients, even if most physiotherapists already put them into practice without knowing it.

But it is still useful to emphasize it and to put it in writing. We don't always do what we know intuitively, and this charter is a reminder of what a good therapeutic relationship must be. It invites us to ask ourselves, for instance: is now a good moment to impose bracing on a child who tells us he or she cannot bear it anymore? Couldn't we listen to this complaint and make a « pact » in which everyone agrees to do it as part of the next session instead?

The charter reminds us that it is important to listen to children, because we tend to hear the parents first. It draws our attention to people who have communication and language deficiencies: we must be even more careful when putting into practice the charter's principles with them.

I also see this charter as a tool to support dialogue with parents. Sometimes they too don't listen to their child enough, because they want to do the right thing, and want the child to progress. Referring to the charter should lead to a dialogue that takes into account what patients have to tell us.

The charter is also a way of promoting access to care for patients. It must help us to bear the message that we need means to implement it. The fact that public authorities signed it is a positive sign, but it must be more than a statement. We lack professionals who are committed: cerebral palsy is a pathology that requires time, and the duration of sessions (30 minutes, when we would sometimes need 1h30), and their timings, are not adapted. For many therapists, it is not economically viable.

So I would suggest that we plan a review in two or three years to measure what changed and what needs to be fixed.



Account: Jean-Bernard Sicard, patient
There is still so much to be done!

For me, who must follow physiotherapy sessions every day, this charter is only a first step, because there remains one key question that is not addressed: how do we ensure that physiotherapists are trained for cerebral palsy and don't find themselves helpless with patients like me? Today, cerebral palsy is only an option in physiotherapy training course.

To that end, the question of means is crucial. The physiotherapist occupation is not considered enough, for instance my 45-minute sessions are paid 21.5 euros gross! We should compensate these acts more to acknowledge their importance and invite therapists to train.

So we must go further than a charter of good practice to allow for appropriate care for patients.



A word from the president

Make a donation to the foundation, give future a chance!

Dear friends,

Open new perspectives for children with cerebral palsy!

The foundation is true to its word. Listening to families, it allowed new research teams to emerge and supported their work. It committed for four years to the European CAP' project to demonstrate the transforming power of intensive playful rehabilitation programs in newborns. It mobilizes researchers on early screening with its new call for projects; it creates new paths with multiple partners.

With Steptember this year, we also gathered more than 1000 persons and 30 companies. All attended to promote the mobility challenge for health, and the generosity challenge.

What help would you want to give us?

- Make a generous donation now to fund CAP'
- Pay a monthly subscription to support our new call for projects
- Make a bequest to the foundation so it can continue to work as long as needed.

Everyday, 4 children are born who will live their whole lives with cerebral palsy. Your donation is for you, and for us, a way to act for them.

Give future a chance!

Thank you from the bottom of our hearts.

Dr Alain Chatelin

CAP' Project: first steps achieved

The CAP' project aims to evaluate the efficiency of intensive playful rehabilitation on newborns, compared with traditional rehabilitation protocols.



The first course including 1-to-4-year old children took place in March 2019 in Brussels. During two weeks, 18 children with unilateral cerebral palsy benefited from several hours of rehabilitation per day, according to functional therapeutic objectives determined with parents and children themselves: climbing stairs, getting dressed alone or using a dandy-horse, for instance. A second course is planned in November/December 2019 in Brest and 16 children also with unilateral CP will take part.

These courses are an occasion for children to make new motor acquisitions and for parents to observe their progresses in matters of autonomy. It is based on play to maintain children's motivation.

* CAP': changes induced by HABIT-ILE therapy in preschool children with cerebral palsy

* HABIT-ILE: Hand and Arm Bimanual Intensive Therapy Including Lower Extremities

Second call for a great joint research project

The foundation launched in May 2019 a new call for proposals. Endowed with a global envelope between 500k and 1.5M euros for a 3-to-5-year period, this second call for a great joint project will allow support for works aiming to improve diagnostic capacities and/or early screening of cerebral palsy and its associated troubles, from the prenatal period to the end of adolescence. It concerns collaborative projects gathering multidisciplinary teams. Applications, expected before the end of December 2019, will be evaluated by international experts during the year 2020. It is important because making a very early diagnosis gives us the best chance of an intervention that preserves the future.



Lucas Ravault, physiotherapist, recipient of a grant from the foundation

Knowing children's background is a key element to help us direct families and to improve the organization of health. The foundation has therefore decided to fund the work of Lucas Ravault, physiotherapist. Under the supervision of Dr Anne Ego, his PhD in public health and epidemiology, carried out in the research lab TIMC-Imag at the University of Grenoble, will make an inventory of care and sport pathways in children with CP in Isère and Savoie; examine the role of intensive rehabilitation in care in this region compared with other places in Europe; and finally inquire about how much physiotherapists know of evidence-based practice and how they see their role with children with cerebral palsy.



Steptember: a successful first French edition

Created in 2010 in Australia, Steptember is a worldwide fundraising operation for research on cerebral palsy. For this first French edition, organized by La Fondation Paralysie Cérébrale, more than 1000 participants met the challenge with us: walking at least 10 000 steps a day for the entire month of September.

With 253 454 523 steps, that is nearly 165 000 kms (four times the earth's circumference), our brave walkers collected more than 65 000 euros for research. Congratulations to them, and see you next year to walk even further!



(from left to right) Mélanie, Angélique, Clémence and Clara, the foundation team is motivated!

More information on www.steptember.fr

Generosity at the Beauty Dinner

The traditional Beauty Dinner, which brings together the greatest perfume houses every year in October, was attended by 220 persons in the Pavillon Wagram.

Their generosity allowed to collect 147 000 euros for research on cerebral palsy.



Our heroes run for research



Once again this year, they impressed us! For our 10th participation in the Heroes race, the 80 runners, wearing the colours of the foundation and its partners – COGEFI, ENVOLUDIA, Les Amis de Mattéo and the Bar of Hauts-de-Seine collected 75 000 euros for research, in particular for the CAP' project on rehabilitation.

Many thanks to them and see you in 2020!