



## What role for the scientific council?

Responsible for clarifying the foundation's research strategy, and for selecting the calls for projects winners, the Scientific Council is made up of recognized experts. It currently welcomes a representative for persons concerned by Cerebral Palsy.



**Leader**

The quality of the chosen research projects and the consistency of the objectives that are set give its meaning to the work of the foundation.

Scientific evaluation is the first mission of the Scientific Council: its demanding nature defines the ethics of the foundation. Widely published in very selective scientific journals, the works we supported have proven their quality.

Can we set goals for research? The Foundation has answered "yes", by putting in its status that research "is only useful if it results in real improvements in the life of those who need it".

How to set these goals? Prospective studies led in 2008/2009 listed the expectations of the people concerned with Cerebral Palsy, along with professionals and researchers. Today this exchange still takes place, with the nomination of a representative for families in the Scientific Council.

The Scientific Council is regularly consulted by the Board Meeting on scientific opportunities, as well as the best ways to use the foundation's means: we must aim well, and we must choose the fields that will produce an important leverage effect.

### **Alain Chatelin**

President of La Fondation Motrice



**A parent, Eric Bérard, now represents the people concerned within the Scientific Council**

***You are Director of FFAIMC and General Secretary of a parents association (ARIMC Rhône-Alpes).***

***How do you consider your role in the Foundation's Scientific Council, and what do you think you will be able to bring, compared to the other members- researchers and practitioners?***

I have committed myself to these associations because I am the father of a son who has suffered from Cerebral Palsy since birth, in 1973- as well as three other children. Supporting my son, protecting him, directing him through his life and medical journey has made me aware that certain answers in medical, nursing and rehabilitation practices were inaccurate. I was capable of changing my views about quality of life. I learned not to rank life habits according to my own criteria. I saw the desire for death and the thirst for life. I believe that, with that package, I can submit to the other members of the Council a representation of the people with Cerebral Palsy in their singularity.

***You are going to represent all the people concerned, not only your family and your association, how do you contemplate this transition?***

The singularity of my situation cannot make me forget that I work in a daily basis for more than 800 persons and their families, to handle their specific needs. This role gives me a good perspective on life in an institution as well as life at home, with the help of professionals. The technical and humane experience I acquired in my association was widely completed by the exchanges that took place in the FFAIMC. By listening and making proposals, I was made aware of the universal stakes in matter of care. Practices are diverse since they don't always rely on scientific bases, and many professionals and parents demand some marks. So I'm highly motivated to bring this question from the ground to the Scientific Council's level.

***In the ARIMC Rhône-Alpes you are in charge, among other things, of questions regarding well treatment and ethics. Is this a topic you would like to deal with within the Scientific Council?***

Well treatment is inseparable from ethical reflection, but both cannot be confused.

For me, ethics are an aim, while well-treatment is a rule, a practice. Ethics, as we consider them in the ARIMC, are the research of a better way to live together, in a "fair institution" (to quote Paul Ricoeur). It deal in life, love and death.

Regarding well treatment, I believe it will be important to improve professional practices. It starts with an evaluation of all practices, leading us to determine which ones must be implemented.

The practitioner in physical medicine and rehabilitation that I am knows what deficiencies and disabilities are (amongst others, thanks to the work led by P. Wood in the 1980s). But it is as the father of a child with Cerebral Palsy that I can best speak of social handicap. All work willing to fight this handicap will surely bring more humanity.

**The Scientific Council: a central authority responsible for guiding and validating our research strategy on Cerebral Palsy.**

The constitution of a new team in 2014 is the occasion to take a look at the Scientific Council's mission, with its President Pr Marc Tardieu.



***The last calls for projects led by La Fondation Motrice were directed to its priority research areas: pain and cognitive troubles mostly. The call for projects 2015 seems broader: is it a sign that research priorities are evolving?***

For years we have alternated thematic calls for projects with “blank” (i.e. without well-defined theme) ones. This alternation is normal and necessary: it prevents us from missing a promising field. We must remain open in order not to miss anything, and sometimes we must “narrow” the subjects to serve best the foundation's research strategy.

***What is the “roadmap” given to the new team?***

This new Scientific Council has the same mission as the previous ones: to bring its scientific expertise to the Board Meeting, who defines the foundation's strategy. Our first objective is to select good projects, among all the applicants, and to build the next call for projects for spring 2015. We will also help organizing the Foundation Days, in March 2015.

The role of the Scientific Council is also to make people understand that research takes time: there is a lot of work, from the expectations expressed by the patients, to the drafting of the calls for projects in such a way that they meet these demands as well as the foundation's strategy. Our role is to make sure that, in the long run, everyone's expectations will be taken into account: those of the patients, children and adults, as well as the parents, and that all subjects (pain, ageing...) will be addressed.

***What was your motivation for integrating a representative for families in the Scientific Council?***

It is a “rule” for all foundations and associations created around a specific pathology: the people concerned must be represented in the Scientific Council, mostly because it would be unthinkable to lead trials without consulting them.

Among the applicants, the foundation chose a representative of the families. His vote has the same weight as the other members, so he will have the same influence as all of us on the choices to be made.

**Composed of internationally recognized researchers and practitioners, the Scientific Council illustrates the multidisciplinary required to understand Cerebral Palsy.**

Created at the same time as the foundation, the Scientific Council is consulted about research themes and the relevant modes of action from a scientific perspective. It also helps selecting the winners of the different calls for projects.

It is composed of 10 members chosen for their expertise and their legitimacy on an international scale, familiar with multidisciplinary work in their clinical practices or their own research works.

Since 2014, The Scientific Council is presided by Pr Marc Tardieu, neuropsychiatrist, member of the council since its creation.

For the first time, in 2014, the Scientific Council welcomes among its members a representative for persons concerned with Cerebral Palsy.



**Dr Valérie Achache, PhD**  
France, Saint-Maurice  
Physiotherapist, engineer  
Motor troubles specialist



**Pr Olivier Baud**  
France, Paris  
Neuropsychiatrist  
Neuroprotection of the developing brain  
specialist



**Mr Eric Bérard**  
France, Lyon  
Representative for the people concerned



**Dr Sylvain Brochard**  
France, Brest  
Doctor in Pediatric Physical Medicine and  
Rehabilitation (PMR)  
Orthopedic complications and pain prevention  
specialist



**Dr Joël Fluss**

Switzerland, Geneva

Neuropediatrician

Neurodevelopment and the consequences of cerebral damage on cognitive capacities specialist

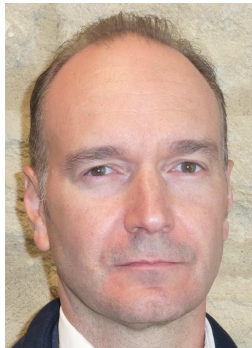


**Pr Jean-Michel Gracies**

France, Créteil

Doctor in PMR, neurophysiologist

Movement neurorehabilitation specialist



**Dr Etienne Jacotot, PhD**

France, Paris – UK, London

Doctor in immunology

Cellular mechanisms of cerebral and neuronal damages specialist



**Pr Ingenborg Krägeloh-Mann**

Germany, Tübingen

Neuropediatrician

Cerebral damages and neuroimaging specialist

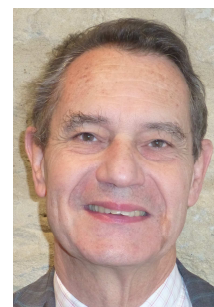


**Dr Javier de la Cruz**

Spain, Madrid

Epidemiologist

Coordinator of the european network of epidemiologic monitoring of Cerebral Palsy in Europe



**Pr Marc Tardieu**

France, Paris

President of the Scientific Council

Neuropediatry

Neuroimmunology specialist



## The Scientific Council: facts and numbers

**10 members** nominated for 4 years, renewed by half every 2 years. The president is nominated for 2 years, renewable once.

**2 plenary sessions** each year, supplemented by teleconferences

**8 calls for projects** since 2005, one call for projects running

**More than 50 projects** funded in France and in Europe, having led to **more than 70 publications** in international scientific journals.

A collective and multidisciplinary body, the scientific council:

- helps define the research strategy, by giving the Board Meeting scientific information, and by being consulted on the foundation's means orientations
- defines the calls for projects' wording in the frame of the themes and budgets decided by the Board Meeting
- evaluates the projects of the applicant teams and suggests laureates to the Board Meeting
- evaluates the intermediary reports and the results of the projects supported by the foundation
- brings its expertise to solve the scientific and medical questions asked to the foundation
- represents the foundation in scientific congresses
- relieves the works of the foundation, and of the researchers supported
- suggests the scientific program of the Foundation Days.

## 2005-2015: ten years of research, ten years of progress

The event “Les journées de La Fondation Motrice 2015” is the occasion to review the progress made by research on cerebral palsy, 10 years after the first calls for projects.

Organized under the aegis of the Scientific Council, “Les journées de La Fondation Motrice” bring together, during two days, experts and researchers from the whole world around a specific theme. It is the occasion to exchange, to communicate about the state and the progress of research, and to mobilise researchers around this theme.

The 2015 edition will be notable for handling all the last 10 years' priority fields of research

- prevention of cerebral damages and their complications,
- pain treatment and prevention,
- remediation and new approaches in rehabilitation,
- progress in cerebral imagery,
- multidisciplinary handling of cerebral palsy.

Alternating short movies (personal stories) with conferences and round tables, these days are open to researchers, practitioners, but also families, public authorities and all who feel concerned with Cerebral Palsy.

**"Cerebral Palsy Days", March 13 and 14, 2015. Pasteur Institute, Paris.**

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

La Fondation Motrice, Research into Cerebral Palsy 67 rue Vergniaud, 75013 Paris, FRANCE Registered as a "government-approved and endorsed public foundation" in July 2006

President : Dr. Alain Chatelin

Vice-President : Mrs Lucie Hertz-Pannier

Patron : Mr Andrea Casiraghi

Founders : Apetreimc (2005), SESEP (2005), CDI (2005), Passer'aile Apetreimc (2006)