

THE THIERRY LATRAN FOUNDATION

European Foundation dedicated to research in the fields of ALS and motor neurons
Under the aegis of Fondation de France



THIERRY LATRAN

Thierry Latran is a 47 years old investment banker, ill and under riluzole since April 2008. Encouraged by friends (industrialists and private equity investors), he set up a Foundation with one single objective in mind : to gather resources in order to promote and finance the best research in the fields of ALS and motor neurons. "There is a lot of human support, friendship, passion and eagerness to succeed. A willingness to fight, build up and expand the scope of the Foundation - while I am alive and after me - like a true company, promoting excellence, efficiency and results."

An initial 120 donors have signed up for grants of €7 millions over the next 10 years. The quest for more financing for the Foundation goes on under the impulse of Thierry.

A TRUE EUROPEAN FOUNDATION SET UP IN JUNE 2008

Thierry Latran Foundation is a non-profit-making organization placed under the aegis of Fondation de France, thereby implying full transparency, certification of the Foundation accounts and a corporate governance respecting Fondation de France strict book of rules. In line with Thierry Latran Foundation true European scope, transnational gifts are encouraged through the Transnational Giving Europe Network, ensuring that donors can benefit from their own domestic tax deductibility schemes.

Dedicated **exclusively** to research in the areas of Amyotrophic Lateral Sclerosis and protection of motor neurons, the Foundation presents the other following distinctive features :

- An initial term and financing for 10 years
- Governed by Fondation de France by-laws and Internal rules
- Comprised of an Executive Committee and a Scientific Advisory Board
- Objective is to distribute the full amount of donations to Research Programs, keeping administrative expenses to an absolute minimum.

EXECUTIVE COMMITTEE

College A, representing the Founder

- THIERRY LATRAN, Founder
- MARIE-FRANCE DUBREUIL, P.A. to Founder
- LUCE GENDRY, Investment Banker
- GRÉGOIRE GONNORD, Industrialist
- DOMINIQUE MOORKENS, Industrialist
- MARC SENOBLE, Industrialist

College B, comprised of Scientists

- ANTOINE BÉRET, Entrepreneur (biotech sector)
- Pr JEAN-PIERRE CHANGEUX, Emeritus Professor at Collège de France, Emeritus Professor at Institut Pasteur, Member of Académie des Sciences
- Dr LAURENT GANEM, Venture capitalist
- Pr JULIEN MENDLEWICZ, Neuropsychiatrist, Chairman of the European Brain Council, PhD in molecular genetics, Professor at University of Brussels
- FRANÇOIS FLORIMOND DESPREZ, Industrialist (biotech sector)

College C, comprised of independent representatives

- THIERRY CONSIGNY, Entrepreneur (advertising)
- MICHEL FRIEH, Lawyer
- PIERRE GAGNAIRE, Starred restaurateur
- GUILLAUME KUPERFELS, Lawyer
- XAVIER MORENO, Venture Capitalist
- CAROLINE PACQUEMENT, PR Manager





THE FOCUS OF THE FOUNDATION IS TO ENCOURAGE AND SUPPORT HIGHLY INTERACTIVE, HIGH-QUALITY EUROPEAN RESEARCH.

THE FOUNDATION SCIENTIFIC ADVISORY BOARD

PR. WIM ROBBERECHT (Leuven University, Belgium), Chairman

PR. CATERINA BENDOTTI (Mario Negri Institute, Milano, Italy)

PR. LINDA GREENSMITH (University College London, United Kingdom)

DR. EVA HEDLUND (Karolinska Institute, Stockholm, Sweden)

PR. ALBERT LUDOLPH (Ulm University, Germany)

PR. VINCENT MEININGER (Salpêtrière Hospital, Paris, France)

PR. LEONARD VAN DEN BERG (Utrecht University, The Netherlands)

• FUNDING RESEARCH PROJECTS

Thierry Latran Foundation wants to encourage in-depth investigation in the fields of ALS and protection of motor neurons as well as innovative approaches

- Selection of projects for financing: projects are reviewed and analysed by the Scientific Advisory Board; respective ratings and a brief report are communicated to the Executive Committee, who then carries out its own review and allocates appropriate budgets to retained applications.
- Grant types :
 - **Major Grants**, circa € 150,000 per year over three years,
 - **Pilot Grants**, circa € 100,000 over two years

• FUNDING A YEARLY MEETING OF ALL GRANTEES

One of the primary goals of the Foundation is to encourage and facilitate interaction between teams involved in ALS research in Europe.

- Therefore, to promote such interaction and collaboration, the Foundation organizes and funds an **annual meeting of grantees** whose research is funded by the Foundation. Such meeting involves attendance of the principal investigator and presentation of the funded research projects, including unpublished data. Strict confidentiality rules and rules to avoid conflicts of interest are adhered to and applied.
- The annual meeting of the Foundation grantees is chaired by the Scientific Advisory Board Chairperson (Wim Robberecht, Leuven University, Belgium). Each principal investigator is required to attend. Additional researchers involved in the project funded by the Foundation are invited as well. This annual meeting is considered as a priority for the Foundation to reach its strategic aims.

FIRST CALL FOR PROJECTS

The first call for projects was launched among the European Neurologist Scientific Community in January 2009.

- 8 PROJECTS SELECTED
- GLOBAL AMOUNT GRANTED : € 1,411,500 FOR 3 YEARS
- OF WHICH € 529,000 FOR THE YEAR 1, € 501,500 FOR YEAR 2 AND € 382,000 FOR YEAR 3

Grantees received selection notification in July 2009. Grants were made available as of 1st September 2009, depending on the effective start of the project.

SELECTED PROJECTS :

1 Novel gene therapy approach for motor neuron disease through broad delivery of death signaling inhibitors by astrocytes.
Patrick Aebischer, Switzerland and Cédric Raoul, France.

2 Characterization of the biochemical and biophysical properties of obligatory dimer proteins representing the two major classes of SOD1 mutants in the *C. elegans* model.
Christian Behl and Albrecht Clement, Germany.

3 Study of the pathological neuro-immune interactions between the macrophages/microglial cells and the affected motor neurons in animal models of ALS.
Séverine Boillée, France.

4 Study of mitochondrial function in experimental models for SOD1-linked familial ALS by genetic manipulation of the p66Shc-dependent molecular pathway.
Maria Teresa Carri, Italy.

5 Investigating the role of Tdp43, recently identified mutated gene causative of ALS, in motor neurons.
Elisabeth Fisher, England.

6 Contribution of Metabolic Dysfunction to Amyotrophic Lateral Sclerosis Pathogenesis.
Jean-Philippe Loeffler and Pierre-François Pradat, France.

7 Translational research into the role of the ephrin system in the pathogenesis of ALS.
Philip Van Damme, Belgium.

8 Role of the transcriptional co-activator PGC-1 α in the pathogenesis of clinical and experimental ALS.
Patrick Weydt and Kerstin Braunstein, Germany.

ABSTRACT ON
www.fondation-thierry-latran.org

2ND CALL FOR PROJECTS

Scientific themes :

Biological markers, pathological pathways and mechanisms, therapeutic strategies, innovative molecules in the fields of ALS and protection of motor neurons for an aggregate amount of up to € 1 million of which up to € 300,000 is dedicated to the specific topic of stem cell therapeutic approaches in ALS.

Eligibility criteria :

- Teams based in Europe or part of FP7 Third Country Agreements as of November 09: Switzerland, Israel, Norway, Iceland, Liechtenstein, Turkey, Croatia, the Former Yugoslav Republic of Macedonia and Serbia, Albania, Montenegro, Bosnia and Herzegovina.
- Transnational projects implying collaborations between several European research teams or institutions to be encouraged.
- Attendance of the principal investigator to the annual scientific meeting of the Foundation to present the funded research project.

Time Schedule

- 2nd call opened: 2nd November 2009
- Deadline for abstract submission: 11th December 2009
- Notification to selected parties for Full Grant Applications: 26th January 2010
- Deadline for receipt of Full Grant Applications: 5th March 2010
- Notification of Grants awarded: 8th June 2010

PLEASE REFER TO OUR WEBSITE
www.fondation-thierry-latran.org
FOR COMPLETE INFORMATION

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Compared to other existing funding bodies and charities for ALS research, what is the specificity of the Thierry Latran Foundation ?

“ I think there is quite a difference between the Thierry Latran Foundation and these national funding bodies, with who the Foundation should be encouraged to collaborate. The Thierry Latran Foundation will be able to support the best research across Europe, without any national barriers. The Foundation represents a major new initiative in European ALS research and I hope it will be a forum to centralize other funding from private sources across Europe. I also hope that the Foundation will very quickly become a key element in ALS research. I am sure that all others ALS funding bodies will be supportive of a new charitable Foundation for ALS research, because they realize that they need additional players in the team against ALS. In these hard financial times, all charitable organizations are very much threatened by reduced budgets at a time when the high costs of genetic studies and clinical trials place an increasing burden on their resources.”

WIM ROBBERECHT

Chairman Scientific Advisory Board
Fondation Thierry Latran