



External Advisory Board

[D 8.3] Creation of the External Advisory Board (EAB)

Project co-funded by the European Commission

DISSEMINATION LEVEL

PU	Public	☒
PP	Restricted to other programme participants	☐
RE	Restricted to a group specified by the consortium	☐
CO	Confidential, only for members of the consortium	☐

1 FINAL COMPOSITION OF THE EXTERNAL ADVISORY BOARD (EAB)

DREAMS has created the EAB that It Is going to Include key stakeholders from the areas of Interest of the project. The members that have been appointed are:

- **Prof Volker Straub** (Deputy Dean, Harold Macmillan Professor of Medicine and Professor of Neuromuscular Genetics at the Institute of Translational and Clinical Research at Newcastle University, Coordinator of the European consortium TREAT-NMD, and more importantly he is the new president of the World Muscle Society),
- **Prof Nicolas Levy** (APHM, expert in neuromuscular disorders and Chief Scientist Rare Diseases in the Pharmaceutical Group Servier),
- **Prof Laurent Servais** (Professor of Paediatric Neuromuscular Diseases at MDUK Oxford Neuromuscular Center, University of Oxford),
- **Prof Hugues Bersini** (Director of the AI Lab of the Université Libre de Bruxelles and co-founder of FARI (FARI | AI Institute for the Common Good, Brussels)).

2 SUMMARY BIOGRAPHY OF EAB MEMBERS

2.1 Prof. Volker Straub

Volker Straub is the Deputy Dean, Harold Macmillan Professor of Medicine and Professor of Neuromuscular Genetics at the Institute of Translational and Clinical Research at Newcastle University, United Kingdom. He is the Director of the university's John Walton Muscular Dystrophy Research Centre and holds honorary clinical appointments with the Newcastle upon Tyne Hospitals NHS Foundation Trust and the North Tees and Hartlepool NHS Foundation Trust. He was the co-founder of the EU FP6 funded network of excellence for genetic neuromuscular diseases, TREAT-NMD, which he coordinated together with Kate Bushby. He is a long standing core member of the TREAT-NMD TACT committee, which offers guidance on the translation and development path of therapeutics programs in rare neuromuscular diseases. Volker Straub is the CI/ PI for a number of natural history and interventional trials in DMD, LGMD, Pompe disease, spinal muscular atrophy and other NMDs. He is part of the steering committee of the MRC Centre for neuromuscular diseases and President of the World Muscle Society. He is an author on >450 peer-reviewed publications in the field of neuromuscular disorders.

2.2 Prof Nicolas Levy

Nicolas Lévy is a clinician and Professor of Human and Medical Genetics, Previously Head of the Hospital Medical Genetics Department (La Timone, Marseille) and director of the Inserm research unit 910 at the faculty of Medicine in Marseille he has been committed to patients affected with rare diseases for over 30 years. In 2009, he was nominated as the director of the French National Institute for Rare Diseases by the Health Ministry, and in February 2012 he created and became the director of the French Foundation for rare diseases. Specialized in genetics of laminopathies and neuromuscular disorders, his team has provided the scientific community with some achievements in these fields. After identifying the LMNA mutation causing the premature aging syndrome named Progeria in 2003, Nicolas Lévy's efforts have been dedicated to the identification of a treatment for rare premature ageing diseases. Pre-clinical explorations showed that a combination of statins and aminobiphosphonates was beneficial in human cells and a mouse model. His efforts are also oriented towards the development of therapeutic strategies in specific muscular dystrophies. Since 2022, Nicolas Lévy, MD, PhD is Chief Scientist Rare Diseases of the Servier Group. His mission is to ensure the acceleration of Servier's research and development pipeline of projects that are focused on small targeted populations of patients with rare and ultra-rare diseases.

2.3 Prof Laurent Servais

Laurent Servais is Professor of Paediatric Neuromuscular Disease at the University of Oxford, and invited professor at the University of Liege, Belgium. After graduating from Louvain Medical School, Brussels, Belgium in 1999, he completed a PhD in Neuroscience (cerebellar electrophysiology in alert living mice) from Free University of Brussels, Belgium, followed by residencies in child neurology at the Free University of Brussels and Robert Debré Hospital, Paris. In 2008, he took a position in neuromuscular disease and clinical research at the Institute of Myology in Paris, where his interest and expertise in neuromuscular diseases flourished. Most recently, he served as Head of the Institute of Myology's I-Motion (Institute Of Muscle-Oriented Translational Innovation), and Head of the Neuromuscular Centre in Liège, Belgium. He have joined MD UK Oxford Neuromuscular Center and the University of Oxford in September 2019. Laurent Servais is involved as principal investigator in numerous clinical trials to test treatments for Duchenne muscular dystrophy and spinal muscular atrophy (SMA).

2.4 Prof Hugues Bersini

Hugues Bersini is Professor in Université Libre de Bruxelles Co-Director of the IRIDIA laboratory and member of the Belgium Royal Academy of Science. Over the last 30 years, he has pionneerly published about 300 papers on his research work which covers the domains of cognitive sciences, AI for process control, connectionism, fuzzy control, lazy learning for modelling and control, reinforcement learning, biological networks, the use of neural nets for medical applications, frustration in complex systems, chaos, computational chemistry, object-oriented technologies, immune engineering and epistemology. At the

European level, Hugues Bersini was the coordinator of the FAMIMO LTR European Project on fuzzy control for multi-input multi-output processes and was involved in two esprit projects: NEMORETS and METHODS that both cover the exploitation of evolutionary and optimisation algorithms for industrial design. These last years, several spin-off have been created out of researches done at IRIDIA such as: Cluepoints, Tevizz and In Silico DB. Hugues Bersini's main research interests are modelling and control of complex systems, neural networks and fuzzy control, data/graph/text mining, autonomous agents and dynamics of biological networks, computational chemistry, immune engineering, cognitive sciences, bioinformatics and object-oriented technology.