**The international umbrella organization NBIA Alliance and its mutual empowerment with the EU-FP7-funded collaborative project TIRCON**

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**INTRODUCTION**

- Neurodegeneration with brain iron accumulation (NBIA) is a group of ultra-rare, transmitter-mediated neurodegenerative movement disorders characterized by high levels of iron in the basal ganglia and a progressive degeneration of basal ganglia neurons.
- The international consortium TIRCON (Translational Iron-Related Childhood-Onset Neurodegeneration, funded by FP7 of the European Commission) was established to generate knowledge for NBIA patients, physicians, and researchers worldwide.
- The TIRCON Consortium is formed of the NBIA Alliance, an international umbrella organization NBIA patient groups, and the European Research Infrastructure on NBIA (ERINOX).

**NBIA ALLIANCE**

- The NBIA Alliance is the first international umbrella organization for NBIA by NBIA patient groups.
- Its main objectives are to increase awareness of NBIA in the health care community and the public, and to support cooperation research among NBIA patient groups.
- The NBIA Alliance is an information platform and a first contact point for patients and clinicians with dedicated structures and has a specific role in implementing science into patient care with thorough knowledge.
- We describe the development, goals, activities, constraints and future research of the NBIA Alliance.
- The NBIA Alliance’s role in the mutual empowerment of the NBIA patient’s movement and the NBIA research community in TIRCON.

**MUTUAL EMPOWERMENT OF TIRCON AND THE NBIA ALLIANCE**

- NBIA patient organizations and related NBIA research groups were forming a cooperation process leading to a full partnership of NBIADA and NBIADA partners in TIRCON and in TIRCON’s effort to incorporate new NBIA patient organizations.
- NBIA patient organizations, in collaboration with TIRCON, have developed a broad-based infrastructure to improve NBIA research and care in Europe and the USA.
- During the development of the NBIA framework, NBIA patient groups joined efforts to establish a framework for NBIA patient organizations and NBIA research groups.
- TIRCON provides an infrastructure for collaborative research and medical care, thus providing hope to patient families and their clinicians.

**CURRENT AGENDA**

- Development of the long-term strategic agenda of the NBIA Alliance.
- Collaborative efforts and increased awareness on all NBIA subtypes.
- Focus on further dissemination of information and tools: websites, patient newsletters, brochures, and educational materials.
- Strategies for enhancing coordination and networking: establishing a centralized data and information system, organizing symposiums, and coordinating advocacy activities.
- NBIA Research and Advocacy: focusing on international awareness and research collaboration.

**RESOURCES THAT WE NEED**

- Funding to employ professional staff because we need to complement the reduced capacity of the NBIA Alliance.
- Management at the NBIA Alliance to establish a strong organizational structure including internal governance.
- Improvement of tools to overcome language barriers because we need to reach out to NBIA communities in different countries.
- A strong action plan for long-term capacity building to strengthen our stakeholders.
- An agenda to act as an international recognized research funding charity.

**GOALS OF THE NBIA ALLIANCE**

- To bring together all NBIA lay advocacy organizations around the world to improve the coordination of their efforts.
- To develop a strategic plan for the future for which will be implemented by all partners to achieve the goals of the NBIA Alliance.
- Help NBIA families cope with rare disorders and enabling them to network on an international level.
- To encourage the growth of NBIA organizations in other countries and to help new developing groups to obtain knowledge and help to reach them.
- To reach the following goals: NBIA Alliance’s impact on TIRCON, to improve the field of iron-related research and disease care.
- Enduring promising collaborative research projects after TIRCON.

**IMPLEMENTATION OF OUR GOALS: POINTS OF DISCUSSION**

- Development of a strategic plan on actions to advance the NBIA Alliance.
- Creation of a legal entity to promote sustainability, public recognition, and funding opportunities.
- Establishment of a NBIA Alliance governance responsible for the setting and implementation of strategic actions in the field of NBIA related biomedical research towards therapy development, networking, and education of clinicians and patients and advocacy in order to improve the NBIA Alliance’s impact.
- Gaining financial support to enable the NBIA Alliance to employ a part-time assistant.
- NBIA research and care: promotion of collaboration of basic and clinical researchers in an NBIA Research Alliance.
- Creation of an NBIA Alliance Scientific Advisory Board that is representative of all countries and the Alliance and supports the goals of the NBIA Alliance.
- Implementation of the NBIA Alliance Research Grants.
- Establishment of an annual NBIA Alliance Research Prize as an incentive for early-career scientists.
- Supporting and enhancing an international clinical infrastructure for NBIA within the framework of quality criteria of national “Centers of Expertise” and “International Rare Disease European Reference Network”, recommended by the EURED.
- NBIA Alliance public outreach.
- Creation of an NBIA Alliance website and an online newsletter to spread our message.
- Development of information packages based on the upcoming "best practice guidelines" for both clinicians and patient families.

**ACKNOWLEDGEMENT**

[Image: NBIA UK logo]