

NBIA Alliance – The Impact of the International NBIA Patient Advocacy on NBIA Research and Vice Versa

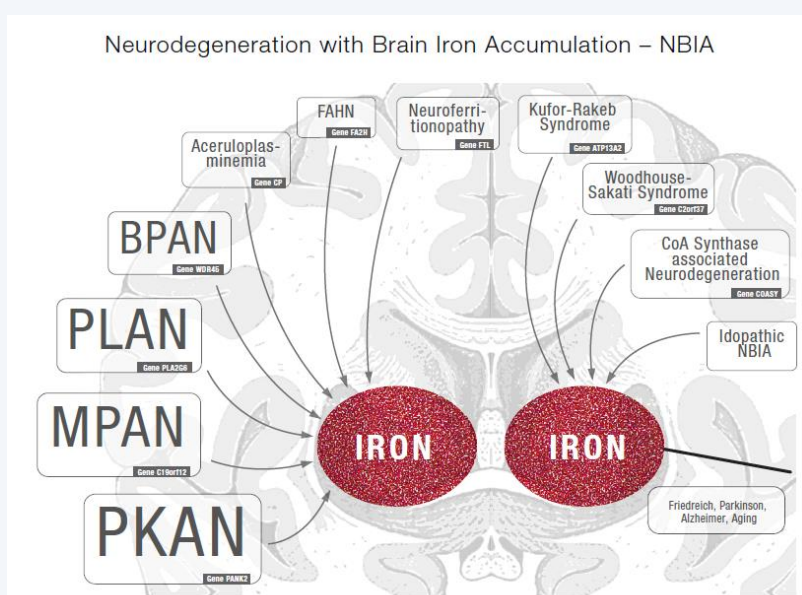


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NBIA

...stands for Neurodegeneration with Brain Iron Accumulation and is a group of **ultra-rare hereditary neurological movement disorders** characterized by high levels of **iron in the basal ganglia** and a progressive degeneration of the nervous system. Currently, there is **no cure or proven therapy** for any of the NBIA forms.

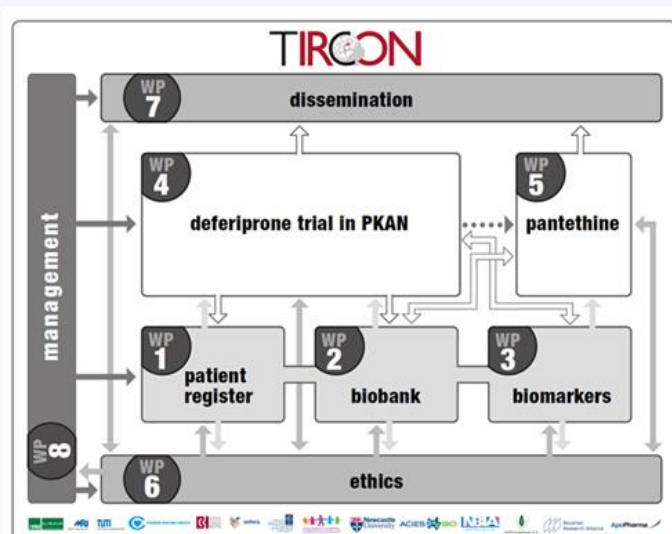


THE NBIA ALLIANCE

...is the first informal international umbrella association for NBIA lay advocacies, currently comprising 7 associations. Its main objectives are to **increase awareness** of NBIA in the health care community and the public, and to **support cooperative research** into NBIA Disorders.

TIRCON

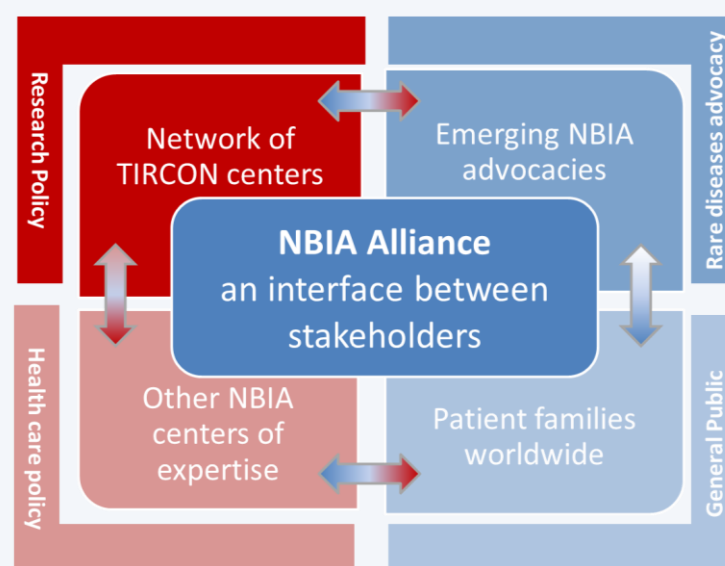
...is an international consortium funded by the EU and investigating NBIA with a focus on **PKAN**. 13 partners from 8 countries are involved in TIRCON (Treat Iron-Related Childhood-Onset Neurodegeneration) including the lay advocacies NBIA Disorders Association (USA) and Hoffnungsbaum e.V. (Germany) as full partners and in charge for dissemination.



TIRCON

IMPACT ON THE ALLIANCE

- Start of the NBIA Alliance as part of TIRCON dissemination at the TIRCON Kick-off meeting 2012
- Inspiration for patient representatives to launch new NBIA patient organizations in Spain, the Netherlands, Canada and UK
- Support of NBIA Alliance meeting and dissemination activities by TIRCON
- Networking NBIA Alliance partners and NBIA experts in TIRCON to enhance the advocacies' dissemination about NBIA research and medical care
- Telemedicine support of TIRCON clinicians to NBIA patients world-wide
- Providing an infrastructure for collaborative research and medical care with benefit for families and advocacies



IMPACT ON TIRCON

Due to their networking capacities, NBIA lay advocacies support TIRCON by...

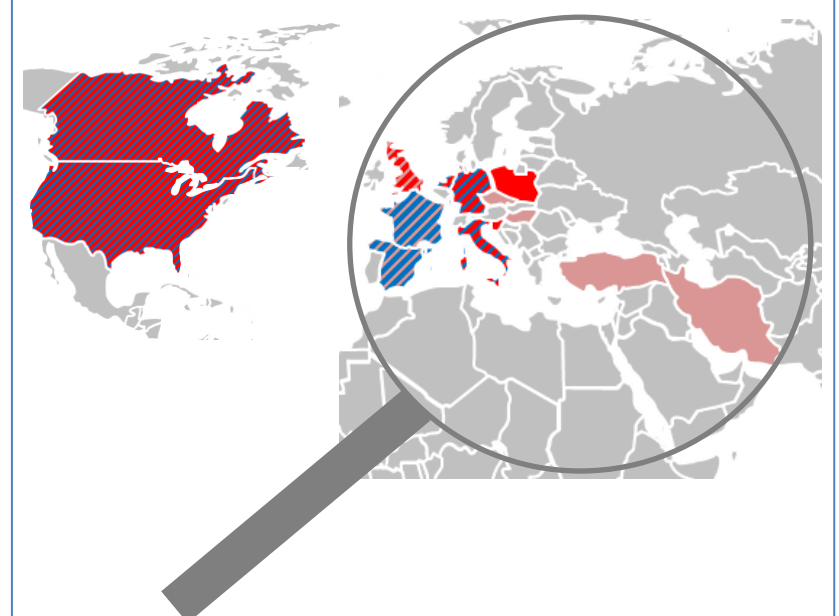
- Contributing patients' needs and views
- Enhancing TIRCON's outreach as multipliers of dissemination activities
- Supporting the patient recruitment for the NBIA registry, biobank and clinical study
- Enlarging the NBIA expert community by identifying new clinical/research centers
- Providing incentives for NBIA research projects and research-related events (e.g. travel grants to NA/NBIA Symposium 2014 for early-career scientists)
- Engaging in a dialogue with stakeholders to raise awareness on NBIA
- Endorsing promising collaborative research projects after TIRCON

CONCLUSIONS

The NBIA patients' movement has an impact on the NBIA research and care community in TIRCON and vice versa.

The NBIA Alliance is...

- along with TIRCON an interconnector between lay advocacy and scientific networks worldwide
- an interface between different stakeholders in both the NBIA and Rare Disease community (see graphics)
- a multiplier of the rising knowledge of NBIA disorders
- a promoter of sustainable, collaborative NBIA research
- a supporter of the development of Best Practices guidelines for all NBIA Disorders



- NBIA Alliance Partners
- TIRCON Consortium
- NBIA Alliance & TIRCON Countries
- Associated Clinical Centers
- NBIA Alliance & Associated Centers
- TIRCON & Associated Centers

REFERENCES

EUCERD Recommendations on Rare Disease European Reference Networks (RD ERNS), 31.01.2013

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NBIA ALLIANCE ONLINE

