



Success Stories of Africa-Europe Research Collaboration in Personalised Medicine

The Egyptian Network for Neurodegenerative Diseases (ENND)



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Executive summary

The **Egyptian Network for Neurodegenerative Diseases (ENND)**, founded in 2013, has emerged as a leading collaborative initiative focused on advancing research on neurodegenerative diseases in Egypt and beyond. Partnering with institutions like the Technical University of Munich (TUM), the German Center for Neurodegenerative Diseases (DZNE), and University College London (UCL), ENND has grown into a multifaceted network spanning Africa and Europe. Key achievements include the discovery of genetic and environmental risk factors for Parkinson's and Alzheimer's diseases, the development of the Egyptian Genome Reference, and the establishment of landmark projects such as the North African Dementia Registry (NADR) and the IPDGC-Africa consortium, which involves 12 African countries. These efforts have been supported by major funding bodies, including the DAAD, Davos Alzheimer's Collaborative (DAC), and the National Institute on Aging (NIA).

ENND's groundbreaking research, published in leading journals such as *Nature Communications* and *The Lancet*, has led to the identification of disease-related genetic variants and biomarkers, paving the way for personalized medicine in the region. The network emphasizes sustainable funding, capacity building, and patient involvement, ensuring its work remains impactful and relevant. Serving as a model for equitable collaboration between Africa and Europe, ENND is advancing the understanding of neurodegenerative diseases while improving diagnostics, treatment, and care tailored to population-specific needs.

Project overview

Our journey began in December 2013 with the founding of the Egyptian Network for Neurodegenerative Diseases (ENND), a collaborative initiative uniting neurology and neuroscience units across Egypt. At this stage, we were focusing on building a critical mass of expertise, visualising where the technical gaps are, and seeking international collaboration, mainly for networking and to help us move forward and maximise the value of our efforts through key partnerships. Partnering with the Technical University of Munich (TUM) and the German Center for Neurodegenerative Diseases (DZNE), ENND's initial aim was to build capacity for neurodegenerative research within Egypt. This foundational partnership laid the groundwork for an evolving success story, expanding our reach and impact far beyond our original vision.

Our early focus was on fostering knowledge exchange, promoting research, and facilitating educational opportunities through seminars, workshops, and international exchanges. This led to the development of several significant projects, each building upon the last and contributing to a deeper understanding of neurodegenerative diseases and the aging process.



Picture 1. Through Egyptian-German collaboration project, the team led by Dr.Mohamed Salama, founded the Egyptian Network for Neurodegenerative Diseases in December 2013.

The first project, the EGI PD Study (Environment-Gene Interactions in Parkinson's Disease), funded by the DAAD, explored the interplay between genetic mutations and environmental factors, specifically pesticide exposure, in Parkinson's disease. This research culminated in the discovery of a novel interactive variant increasing susceptibility to the detrimental effects of pesticides on the brain, a finding published in [Nature](#).

Building on this momentum, the DAAD-funded GeneFINDER project (Genetic Factors for Inherited Neurodegenerative Diseases in Egyptian Regions) further investigated the genetic underpinnings of familial forms of Alzheimer's disease, Parkinson's disease, Essential Tremor, and other neurological conditions. This work led to the identification of various disease-related variants, published in prominent journals, such as [Neurology Genetics](#), [Heliyon](#) and [Neurogenetics](#).

Simultaneously, our collaboration expanded to encompass **the development of the Egyptian Reference Genome**, initially supported by the DAAD and subsequently by the DFG. This landmark achievement resulted in the publication of a comprehensive reference genome for Egyptian subjects in [Nature Communications](#), providing an invaluable resource for future research.

Our international collaborations continued to flourish with **the establishment of IPDGC-Africa**, a partnership with UCL in the UK. This collaboration involved 12 African countries which are Cameroon, Egypt, Ethiopia, Ghana, Mali, Nigeria, Senegal, South Africa, Sudan, Tanzania, Tunisia and Zambia. This initiative fostered the creation of **an African consortium** dedicated to studying the genetic basis of Parkinson's disease, with findings published in [The Lancet](#).

Most recently, ENND has partnered with UCL and the Davos Alzheimer's Collaborative (DAC) to launch the **North African Dementia Registry (NADR)**. This ambitious project aims to unravel the genetic and environmental determinants of dementia in North Africa, further expanding our research footprint and contributing to global understanding of this

devastating disease. This collaboration was highlighted by [UCL News](#) and demonstrates the growing recognition of our work.

In parallel, we are launching the Aging Study of Egypt (AL-SEHA) in collaboration with the EU-based SHARE study, funded by the National Institute on Aging (NIA). This project promises to provide critical insights into the aging process within the Egyptian population.

From a two-partner collaboration, ENND has grown into a **multifaceted network engaging partners across Europe and Africa**. Our research continues to exceed initial expectations, driving towards our ultimate goal: understanding the determinants of neurodegeneration, identifying population-specific risk factors, and developing targeted diagnostic and therapeutic strategies tailored to the unique biological characteristics of our population. Through strategic partnerships and the support of leading funding agencies, ENND is poised to make significant contributions to the fight against neurodegenerative diseases.

Results and findings

Our funding and collaborative efforts have yielded significant advancements in understanding neurodegenerative diseases, particularly Alzheimer's and Parkinson's. We have successfully identified several risk genes, causative genes, and crucial biomarkers, paving the way for personalized medicine and precision health. These discoveries, documented in a comprehensive list of publications (available in the references section), enable patient stratification and the identification of tailored therapeutic and diagnostic targets. This research is now being translated into clinical applications, bridging the gap between scientific discovery and patient care. Currently, leveraging the wealth of multiomics data generated from our studies, we are launching an ambitious exposome project. This initiative aims to correlate multiomics analyses with environmental exposure data, ultimately constructing an exposome network for specific neurodegenerative diseases, further refining our understanding of disease etiology and progression.

Funding of the project

- German Academic Exchange Services (DAAD)
- Michael J Fox Foundation (MJFF)
- National Institute on Aging (NIA)
- Davos Alzheimer's Collaborative (DAC)
- Alzheimer's Association (AA)
- Parkinson's and Movement Disorders Foundation (PMDF)
- Academy of Scientific Research and Technology (ASRT)
- Science and Technology Development Fund (STDF)
- International Brain Research Organization (IBRO)
- International Society of Neurochemistry (ISN)
- International Parkinson's Disease and Movement Disorders Society (MDS)

Current organization and Key partners

- ENND central unit: Institute of Global Health and Human Ecology, the American University in Cairo.
- ENND collaborators: Different Egyptian Universities, including Ain Shams, Mansoura, Cairo, Sohag, Assiut, Benha, Al-Azhar, Suez Canal, Alexandria, and Tanta.
- European Collaborators:
 German Center for Neurodegenerative Diseases (DZNE), Technical University of Munich (TUM), University of Lubeck, Max Planck Institute for Social Law and Social Policy (MPISOC), Survey of Health, Ageing and Retirement in Europe (SHARE), Germany.
 University College London (UCL) UK.
- African Collaboration through IPDGC-Africa: Including research groups from Cameroon, Ethiopia, Ghana, Mali, Nigeria, Senegal, South Africa, Sudan, Tanzania, Tunisia and Zambia.



Figure 1. The Universities in Egypt that have joined the ENND.

Sustainability approach and Future Directions

ENND's success is built upon three key pillars:

1. **Sustainable Funding**: Our ability to communicate the value of partnership, forming joint research groups in Africa with international collaboration, and to secure continuous funding from diverse national and international agencies has been instrumental in maintaining the momentum of our research programs. This

consistent support ensures the long-term viability of our work and allows us to pursue ambitious, impactful projects.

2. **Scientific Credibility:** Our commitment to rigorous research and impactful discoveries has fostered trust and recognition within the scientific community. This credibility has enabled us to expand our network, attracting new members, partners, and collaborators while nurturing existing relationships. This growth strengthens our collective expertise and expands our reach.
3. **Community Engagement:** We recognize the importance of connecting with the patient community we serve. Through support initiatives, awareness campaigns, and health literacy programs, we strive to empower individuals and families affected by neurodegenerative diseases. This engagement ensures our research remains relevant to the needs of those it aims to help.

These interconnected pillars provide a strong foundation for ENND's future, enabling us to continue pushing the boundaries of neurodegenerative disease research and translate our findings into tangible improvements in patient care.

Lessons Learnt

ENND's journey has been a powerful teacher, demonstrating that true success in research arises from navigating challenges and transforming them into opportunities. We've learned that building and sustaining a thriving research network requires:

- **Trust as the Cornerstone:** Open communication, transparency, and mutual respect have been essential in fostering strong, lasting partnerships. Trust is the bedrock upon which our collaborative efforts are built, enabling us to overcome obstacles together.
- **Shared Ownership and Equal Partnership:** We recognize that every partner brings unique strengths and perspectives. Embracing a philosophy of shared ownership and equal contribution ensures that all voices are heard and valued, maximizing the impact of our collective efforts.
- **Continuous Improvement through Capacity Building:** We are committed to fostering growth and development within our network. Through ongoing training, mentorship, and knowledge exchange, we empower researchers and clinicians, ensuring the sustainability and continued success of our work.
- **Patient and Public Involvement:** We understand that research is most impactful when it is informed by the lived experiences of those it aims to benefit. Actively involving patients and the public in our research process ensures our work remains relevant, responsive, and ultimately, more effective.

Expected Impact

ENND represents a unique and impactful model for neurodegenerative disease research in the region. By fostering collaboration and driving scientific discovery, we are advancing the

field and paving the way for precision medicine. Our work has deepened understanding of disease determinants, moving us closer to effective, personalized treatments.

Furthermore, ENND serves as a shining example of successful bidirectional partnership between Africa and Europe. Built on a foundation of equal contribution, mutual respect, and shared learning, our collaborative model can inspire similar initiatives across disciplines and regions. We believe that by working together, sharing knowledge, and empowering local expertise, we can accelerate scientific progress and improve lives globally.

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