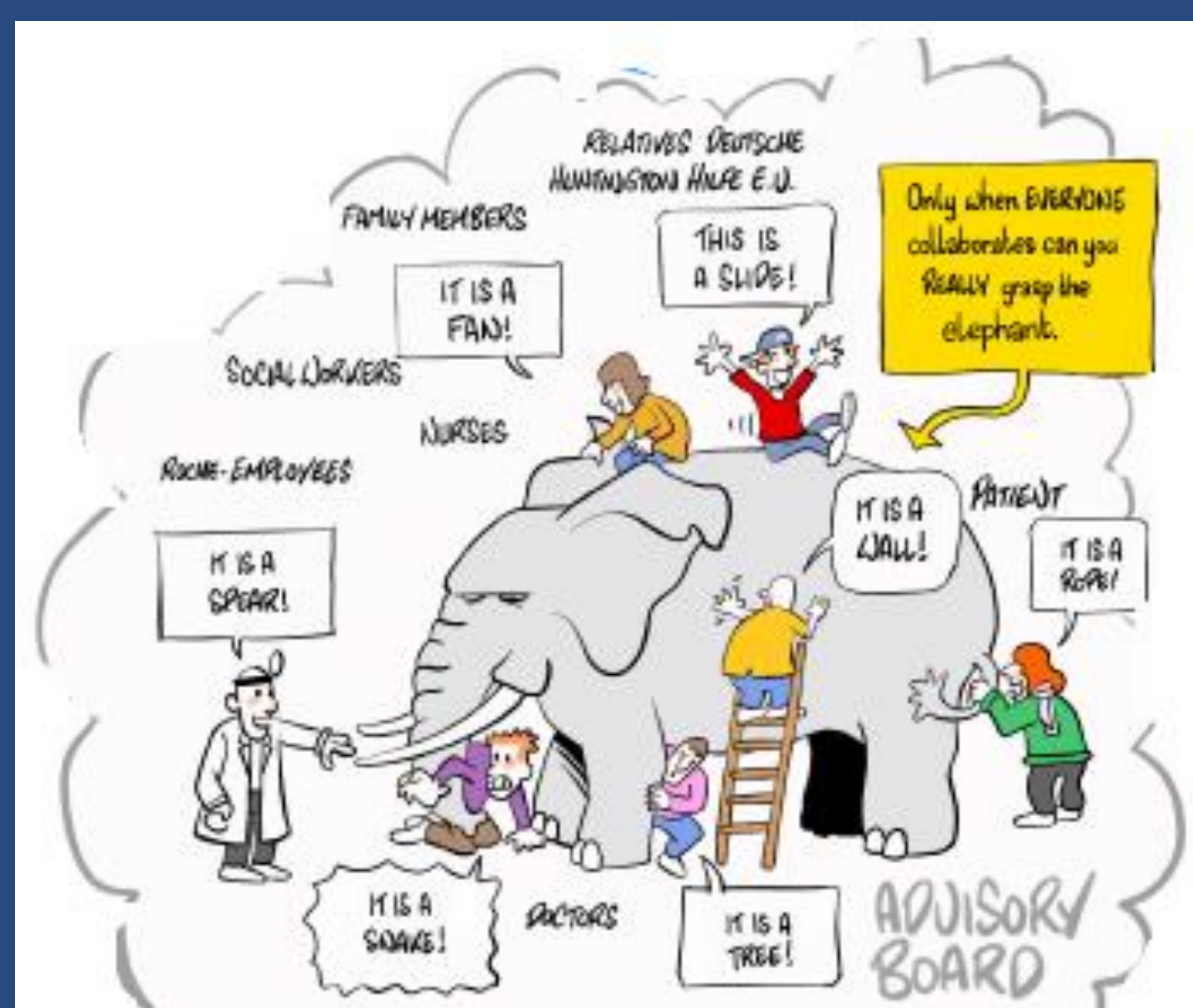


# A JOINT INITIATIVE FOR IMPROVED CARE OF HUNTINGTON'S DISEASE PATIENTS IN GERMANY

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*Diverse stakeholders of the HD community are collaborating: patients, families, patient organizations, various medical and therapeutic specialties, and researchers. The jointly identified and defined activities aim to offer an integrative multidisciplinary treatment concept in the future. This is intended to meet the needs of HD patients over all stages and their families in Germany.*



**Current HD Care in Germany means lots of engaged and competent stakeholders who get only their own piece of the elephant.**

## Background

- Huntington's Disease (HD) is a neurodegenerative, progressive disease caused by a gene defect.
- In Germany approximately 8.000 - 12.000 people suffer from clinically manifest HD.
- So far, no interventional treatment option to stop or slow the progression of HD is available. However, patients benefit both in functional status and quality of life from existing treatment and support options.
- Due to the complexity of HD, people of many different disciplines are involved in the treatment. Moreover, disciplines change with the different stages of the disease. Unfortunately, there are no established channels to communicate sufficiently with each other. No comprehensive documentation of all people involved over the time is accessible - and as a consequence no one is able to get the complete picture "of the elephant".
- Still not all patients have access to all therapeutic and supportive options for various reasons (i. e., no HD site nearby, GPs have a lack of information and are so far rarely part of the HD network) There are no defined pathways for multidisciplinary HD therapy and care in Germany.

## Aims

- To provide a comprehensive multidisciplinary treatment concept covering all HD patients' stages.
- Start, enable and intensify collaboration of different stakeholders: patients, families, patient organization, various medical and therapeutic specialties as well as researchers.
- Identification of HD community needs as well as start of activities to improve multidisciplinary treatment in HD and to support HD families in their daily life.

## Acknowledgment

We would like to thank Roche Pharma AG Germany and all stakeholders for their continued support of the activities described.

## Disclosures

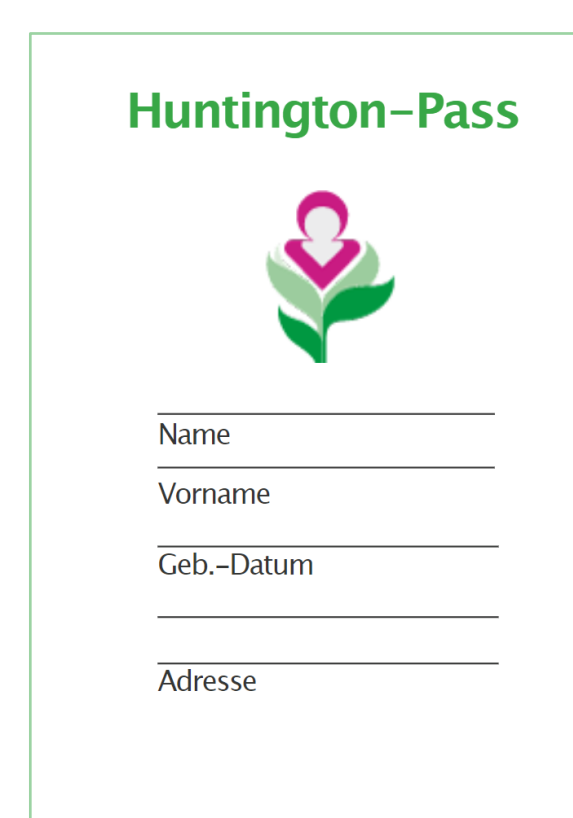
The mixed advisory boards, the production of the HD educational book and the production of the radio spot were kindly financially supported by Roche Pharma AG Germany.

## Methods & Procedure

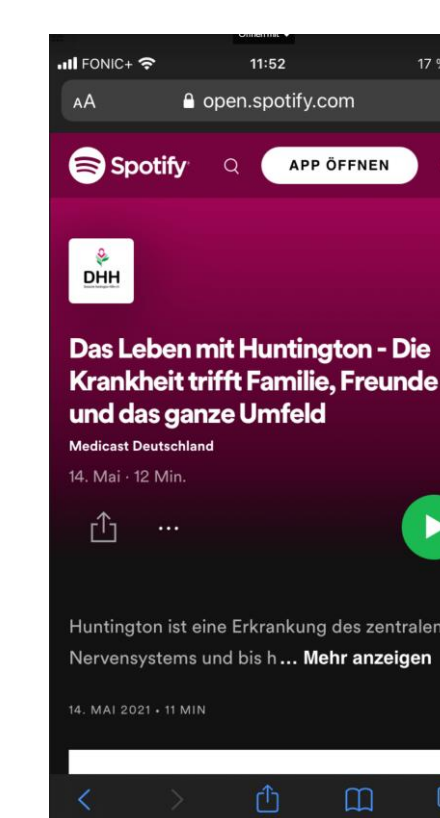
- In 2020 the German HD Patient Advocacy Group (Deutsche Huntington-Hilfe DHH) and Roche Pharma AG Germany conducted two mixed advisory board meetings. Various stakeholders affected by Huntington's disease were invited as advisors, i. e., HD therapy experts, office based and hospital-based neurologists, nurses, social workers, patient advocates, HD patients and family members.
- During the first meeting people learned to know each other and shared their respective experiences, unmet needs and future wishes related to HD.
- Based on these findings, focus areas for improvement were identified and prioritized.
- In the second mixed advisory board meeting, the attendees continued to develop the topics.
- As a result, the following working groups were established with additional experts in specific roles: 1. disease awareness & stigma, 2. networking, 3. multidisciplinary therapy, 4. training, 5. capacity for emerging treatments (on hold), 6. publication of a position paper and 7. development of a HD educational book for professionals.
- The individual working groups meet regularly and have already defined goals and produced initial results or interim findings. All groups have organizational speaker teams that prepare and follow up on meetings. In addition, there is a meeting of all speaker teams to ensure the exchange across all working groups.
- It is special and unique that all members of the multi-professional working groups are co-creating voluntarily, because they all are committed to the common goal of improving the conditions of HD families.

## Outcomes

- Drafting a position paper that defines further recommendations for the multidisciplinary care approach in HD (about to be submitted to NeuroTransmitter - leading journal of the three German associations in neurology and psychiatry)
- Various disease awareness activities in May 2021 (i.e., illuminations of various buildings all over Germany, podcast & radio spot, reached more than 3 million people)
- Publication of HD educational book for professionals in progress.
- Evaluation of educational training needs of HD families as well as medical and therapeutic specialties started (i.e., questionnaire for families and HD professionals)
- Draft position paper on the goals and future of multidisciplinary therapy in Germany (how should HD care in Germany be structured?)
- Preliminary concept for nationwide establishment of sufficient intrathecal therapy options in Germany with convenient access for patients as well as fair and attractive reimbursement based on the results of market research studies
- Development of medical materials and platforms for interdisciplinary clinical routine started (i.e., HD Patient ID Card).



HD Patient ID Card containing all relevant information from different therapists in one document.



HD Awareness Podcast (accessible via various platforms like Spotify).

## Conclusions

- A common journey has been started, which lives through the unique commitment of each individual.
- The engagement of many different stakeholders in all working groups is unique and we perceive that this creates very special results.
- We work without boundaries and beyond silos.
- Everyone is enabled to bring his/her full potential and as a result, the "elephant" comes alive and becomes tangible and visible to everyone.
- This may lead us finally to a significantly better outcome in order to improve our HD patients' lives.