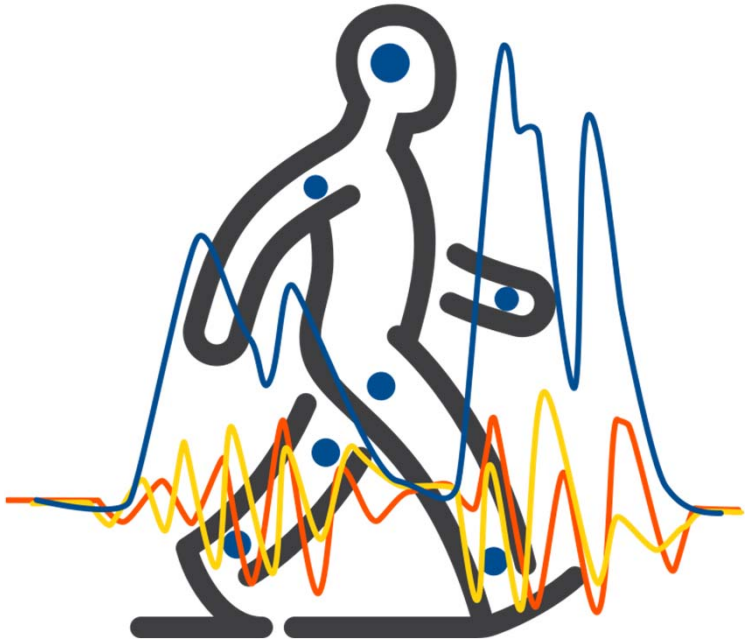
European Reference Network for rare or low prevalence complex diseases
Network Neurological Diseases (ERN-RND)

ean european academy of neurology

European Reference Network for rare or low prevalence complex diseases
Network Neuromuscular Diseases (ERN EURO-NMD)

**DG ‚Chorea and HD‘**
**20. October 2020**

# Joint webinar series

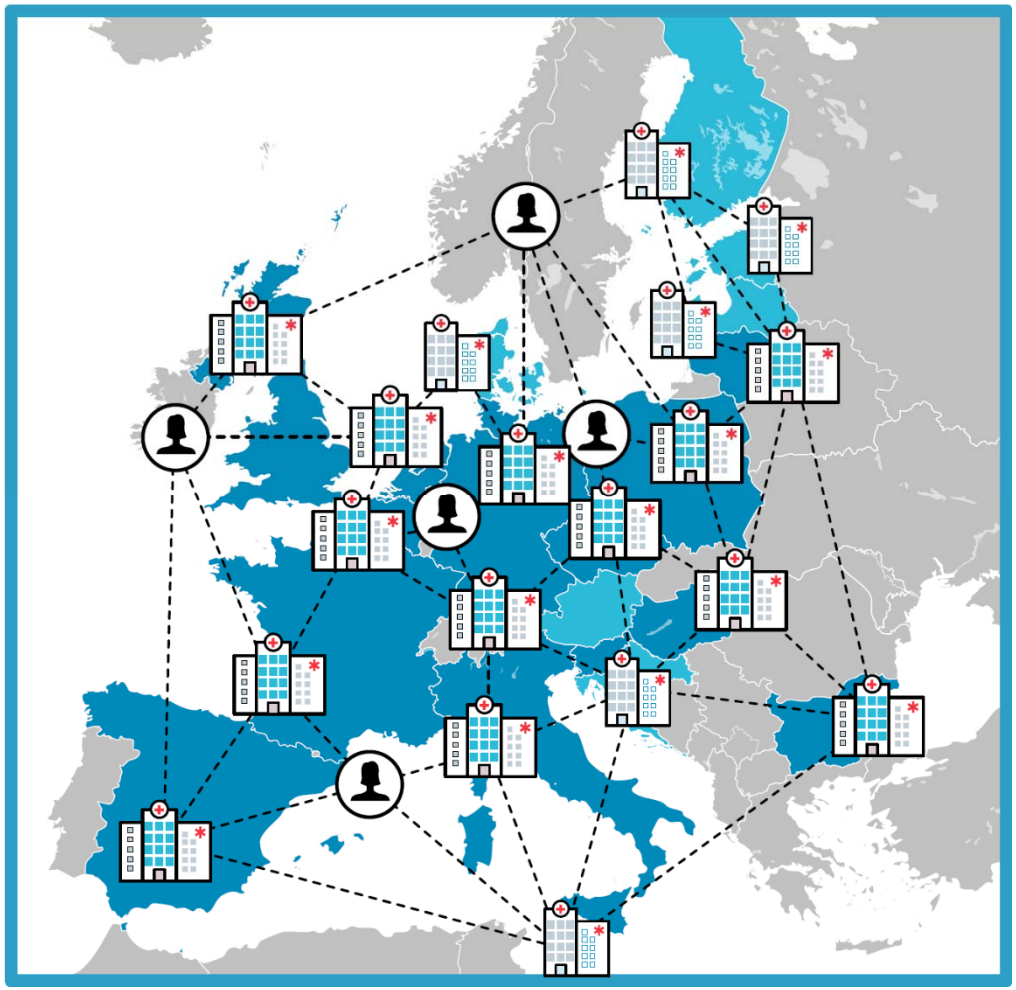


## ‘Clinical practice recommendations for physical therapy for Huntington’s disease’

**by G. Bernhard Landwehrmeyer**
**Department of Neurology, Ulm University, Germany**

# European Reference Network for RARE Neurological Diseases (ERN-RND)

- Countries with Full Members
- Countries with Affiliated Partners



ERN-RND covers 6 disease groups:

1. Ataxia and HSP
2. Leukodystrophies
3. Dystonias /NBIA/Paroxysmal disorders
4. Chorea and HD
5. FTD
6. Atypical Parkinsonism

# General information about the webinars

- Focus on : RARE neurological, neuromuscular and movement disorders and **neurorehabilitation**
- 40-45min presentation
- 15min Q&A session at the end (please write your questions in the Q&A)
- Recorded Webinar and presentation to be found at the latest 2 weeks after on: http://www.ern-rnd.eu/education-training/past-webinars/
- Further information: http://www.ern-rnd.eu/disease-knowledge-hub/choreas-huntingtons-disease/
- Post-webinar survey (2-3min): satisfaction, topic/speaker ideas for next webinars

# ePAG: european Patient Advocacy Groups

## Astri Arnesen

President of the European Huntigton Association

In ERN-RND Patient Advocate for the DG ‘**Chorea and HD**‘

*Show video*

# Speaker: Bernhard Landwehrmeyer

- **Current position:** since 1999 Full Professor of Neurology 'Clinical Neurobiology,' University of Ulm, Germany
- **Training:** MD from the Albert Ludwig University of Freiburg in Germany, with residency in neurology and psychiatry. Additional postgraduate trainings at the Kantonsspital in Basel, Switzerland and a research fellowship at the Massachusetts General Hospital, Harvard Medical School in Boston, Mass., USA.
- **Key positions:**
  - One of the founders of the European HD Network (EHDN: www.ehdn.org) and was Chairman of its Executive Committee in the first ten years since the constitution.
  - Since 2011: Global PI of ENROLL-HD, a worldwide, prospective, observational Huntington Disease (HD) cohort study for HD families, sponsored by CHDI Foundation, USA. (https://enroll-hd.org/)
  - Director of the HD center in Ulm, a multi-disciplinary center providing genetic counselling, clinical in- and out-patient services as well as rehabilitation for HD affected families.
- **Research focus:** neurodegenerative disorders, such as HD and Parkinson disease, ranging from bench work to clinical studies.

Institutional Logo,
‚Speakers' picture or
disease related picture

# Webinar outline

- Introduction:
  - Physical therapy (PT) in rare disorders: clinical IMPRESSIONS versus EVIDENCE for impact/benefit
- PT in the HD context:
  - Clinical presentation & natural history of HD
  - PT as symptomatic therapy/to ameliorate symptoms & signs
  - PT as intervention to modify the course of disease?
    - Short term: rehabilitation
    - Long term: lifestyle
- Challenges ahead

Institutional Logo,
‚Speakers' picture or disease related picture

# Learning objectives

- By the end of this webinar you will be able to:
  - Describe the variable clinical presentations of HD
    - Explain the root cause of this variability
    - Describe the natural history of HD
  - State important PT approaches & interventions
    - Define the intentions motivating PT interventions
  - Understand the current grade of evidence for various PT interventions
  - Describe novel approaches/efforts currently under study
  - Identify practical challenges in implementing PT interventions

EUROPEAN **HUNTINGTON'S DISEASE** NETWORK

# Knowing the audience

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# Physical therapy in rare disorders: Clinical impressions

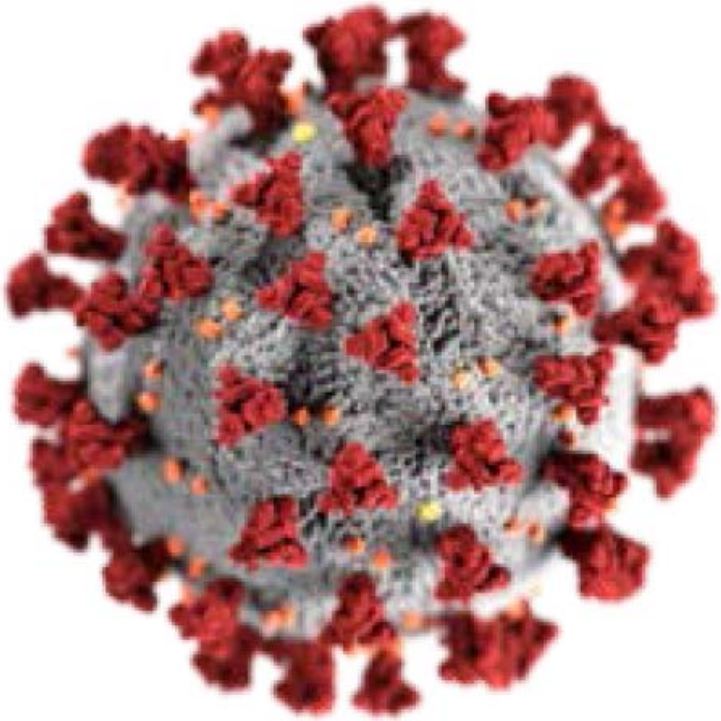
DeWeerdt, *Nature* 2011

PREVENTION

# Activity is the best medicine

*Can exercise, social interaction and the Mediterranean diet really help to keep the cognitive decline of Alzheimer's disease at bay?*

# SARS-Cov-2 pandemic



**‚Evidence' from withdrawal**

- Many patients affected by HD had no access to PT and other co-therapies (OT, speech therapy, occupational therapy) during lock-down.
- The clinical impression is that many patients deteriorated functionally to a clinically relevant degree

**Exercise is beneficial**

*Individuals with HD and their caregivers perceive exercise as beneficial*

*Physical benefits*

- Gait (33)
- Balance (33)

*Social Benefits*

- Self-confidence and independence (33)
- Socialization and improved family and social relationship; reports of new friendships (33)

Fritz et al (2017). *Physical Therapy and Exercise in Huntington's Disease Systematic Review*

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# Physical therapy in rare disorders: evidence

# Evidence supporting exercise and physical therapy in HD

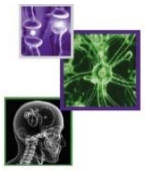
Effectiveness of Physiotherapy, Occupational Therapy, and Speech Pathology for People with Huntington's Disease: A Systematic Review

Belinda Bilney, Meg E. Morris, and Alison Perry

SPECIAL REPORT

Development of physiotherapy guidance and treatment-based classifications for people with Huntington's disease

Lori Quinn & Monica Busse*; On behalf of the members of the European Huntington's Disease Network Physiotherapy Working Group



**Physical Activity Self-Management and Coaching Compared to Social Interaction in Huntington Disease: Results From the ENGAGE-HD Randomized, Controlled Pilot Feasibility Trial**

Monica Busse, Lori Quinn, Cheney Drew, Mark Kelson, Rob Trubey, Kirsten McEwan, Carys Jones, Julia Townson, Helen Dawes, Rhiannon Tudor-Edwards, Anne Rosser, Kerenza Hood

What effect does a structured home-based exercise programme have on people with Huntington's disease? A randomized, controlled pilot study

145 NEUROLOGY REPORT

**Physical Therapy for People with Huntington Disease: Current Perspectives and Case Report**

*Lori Quinn, EdD, PT*
*Ashwini Rao, EdD, OTR*

**Reliability and Minimal Detectable Change of Physical Performance Measures in Individuals With Pre-manifest and Manifest Huntington Disease**

Lori Quinn, Hanan Khalil, Helen Dawes, Nora E. Fritz, Deb Kegelmeyer, Anne D. Kloos, Jonathan W. Gillard, Monica Busse; for the Outcome Measures Subgroup of the European Huntington's Disease Network

**Adherence to Use of a Home-Based Exercise DVD in People With Huntington Disease: Participants' Perspectives**

A Classification System to Guide Physical Therapy Management in Huntington Disease: A Case Series

*Nora E. Fritz, PT, PhD, DPT, NCS, Monica Busse, PhD, Karen Jones, PT, Hanan Khalil, PhD, Lori Quinn, PT, EdD, and the Members of the Physiotherapy Working Group of the European Huntington's Disease Network*

A Randomized Feasibility Study of a 12-Week Community-Based Exercise Program for People With Huntington's Disease

Can directed activity improve mobility in Huntington's disease?

M.E. Busse[a], A.E. Rosser[b, c, d]

**Video game play (Dance Dance Revolution) as a potential exercise therapy in Huntington's disease: a controlled clinical trial**

The effects of multidisciplinary rehabilitation in patients with early-to-middle-stage Huntington's disease: a pilot study

**Task-Specific Training in Huntington Disease: A Randomized Controlled Feasibility Trial**

Client and therapist views on exercise programmes for early-mid stage Parkinson's disease and Huntington's disease

Brain and Behavior — Open Access

**The effect of multidisciplinary rehabilitation on brain structure and cognition in Huntington's disease: an exploratory study**

ORIGINAL ARTICLE

**Effects of multidisciplinary therapy on physical function in Huntington's disease**

Travis M. Cruickshank, Alvaro P. Reyes, Luis E. Penailillo, Tim Pulverenti, Danielle M. Bartlett, Pauline Zaenker, Anthony J. Blazevich, Robert U. Newton, Jennifer A. Thompson, Johnny Lo, Mel R. Ziman

Physical therapy in Huntington's disease – toward objective assessments?

Practice, Progress and Future Directions for Physical Therapies in Huntington's Disease

Effects of a Two-Year Intensive Multidisciplinary Rehabilitation Program for Patients with Huntington's Disease: a Prospective Intervention Study

Effects of an intensive rehabilitation programme on patients with Huntington's disease: a pilot study

2002 2003 2007 2008 2009 2010 2012 2013 2015 2019 2020

# Clinical recommendations to guide physical therapy practice for Huntington disease

Neurology®

Mixed methods systematic review using Joanna Briggs methodology including observational and experimental study designs.

2,377 records identified

2,144 records screened

31 full text-articles assessed for inclusion

18 studies selected based on quantitative synthesis

2 studies selected based on qualitative synthesis

## Grade A Evidence

Aerobic training with or without resistance training → Improvements in fitness and motor function

Supervised gait training → Improved spatiotemporal features of gait

## Grade B Evidence

Exercise improves balance but not fall frequency

Respiratory training improves breathing function and capacity

Caregiver education for maintenance of activity

Transfer training and getting up from floor may be beneficial

Quinn, L., Kegelmeyer, D., Kloos, A., Rao, A., Busse, M., & Fritz, N. (2020). Clinical recommendations to guide physical therapy practice for huntington disease. Neurology, 94(5), 1-12

NRL Neurorehabilitation Research Laboratory

# Recommended reviews

VIEWS & REVIEWS | OPEN ACCESS

## Clinical recommendations to guide physical therapy practice for Huntington disease

Lori Quinn, EdD, PT, Deb Kegelmeyer, MS, PT, DPT, GCS, Anne Kloos, PhD, PT, NCS, Ashwini K. Rao, EdD, OTR/L, FAOTA, Monica Busse, BSc, BSc (Hons) MSc (Med) PhD, PT, and Nora E. Fritz, PhD, PT, DPT, NCS

**Correspondence**
Dr. Fritz
nora.fritz@wayne.edu

*Neurology*® 2020;94:217-228. doi:10.1212/WNL.0000000000008887

A Mixed Methods Systematic Review

Nora E. Fritz[a], Ashwini K. Rao[b], Deb Kegelmeyer[c], Anne Kloos[c], Monica Busse[d], Lynda Hartel[e], Judith Carrier[f] and Lori Quinn[g,*]

# Resources

EUROPEAN HUNTINGTON'S DISEASE NETWORK

PHYSIOTHERAPY CLINICAL GUIDELINES

Huntington's disease

European Huntington's Disease Network Physiotherapy Working Group

Engage-HD

Move TO EXERCISE

CARDIFF UNIVERSITY PRIFYSGOL CAERDYDD

ENGAGE-HD

PHYSICAL ACTIVITY WORKBOOK

ENGAGE-HD study team: Dr Monica Busse, Dr Lori Quinn, Professor Helen Dawes, Dr Carys Jones, Dr Mark Kelly, Professor Kerenza Hood, Professor Rhiannon Tudor-Edwards and Professor Anne Rosser.

www.hda.org.uk/professionals/resources-for-professionals/best-practice-in-huntington-s-disease

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# Physical therapy in the context of HD

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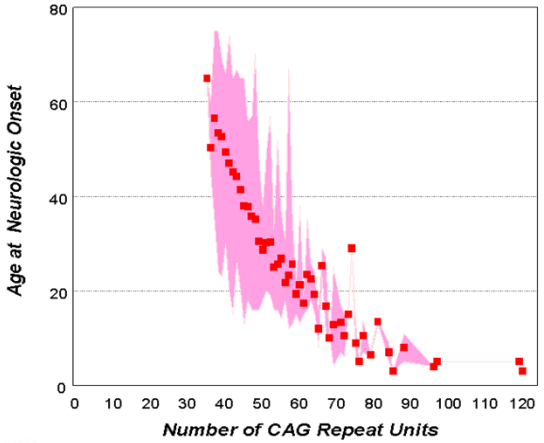
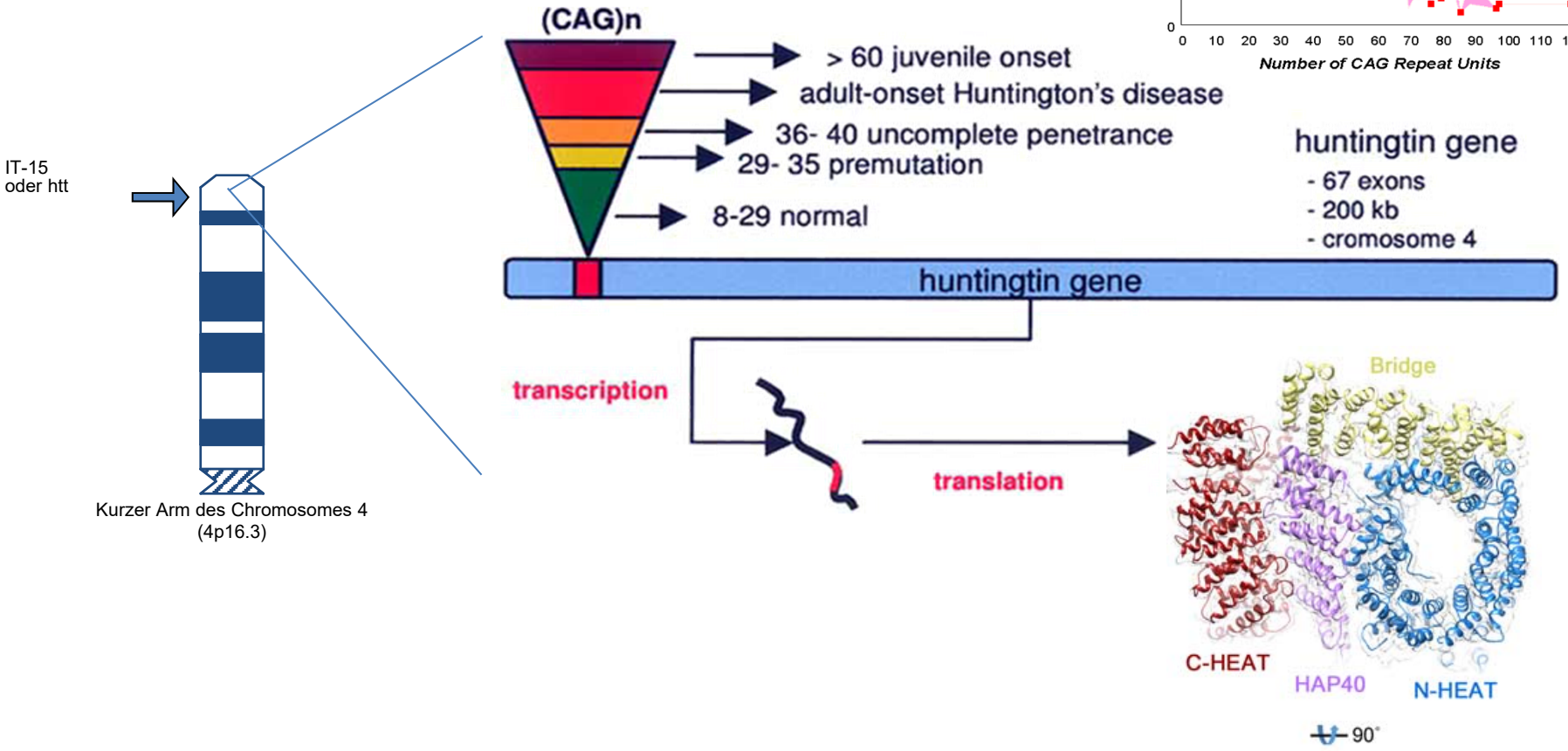
# The clinical presentation of HD is variable …

# … despite the fact that HD is a mono-genetic disorder



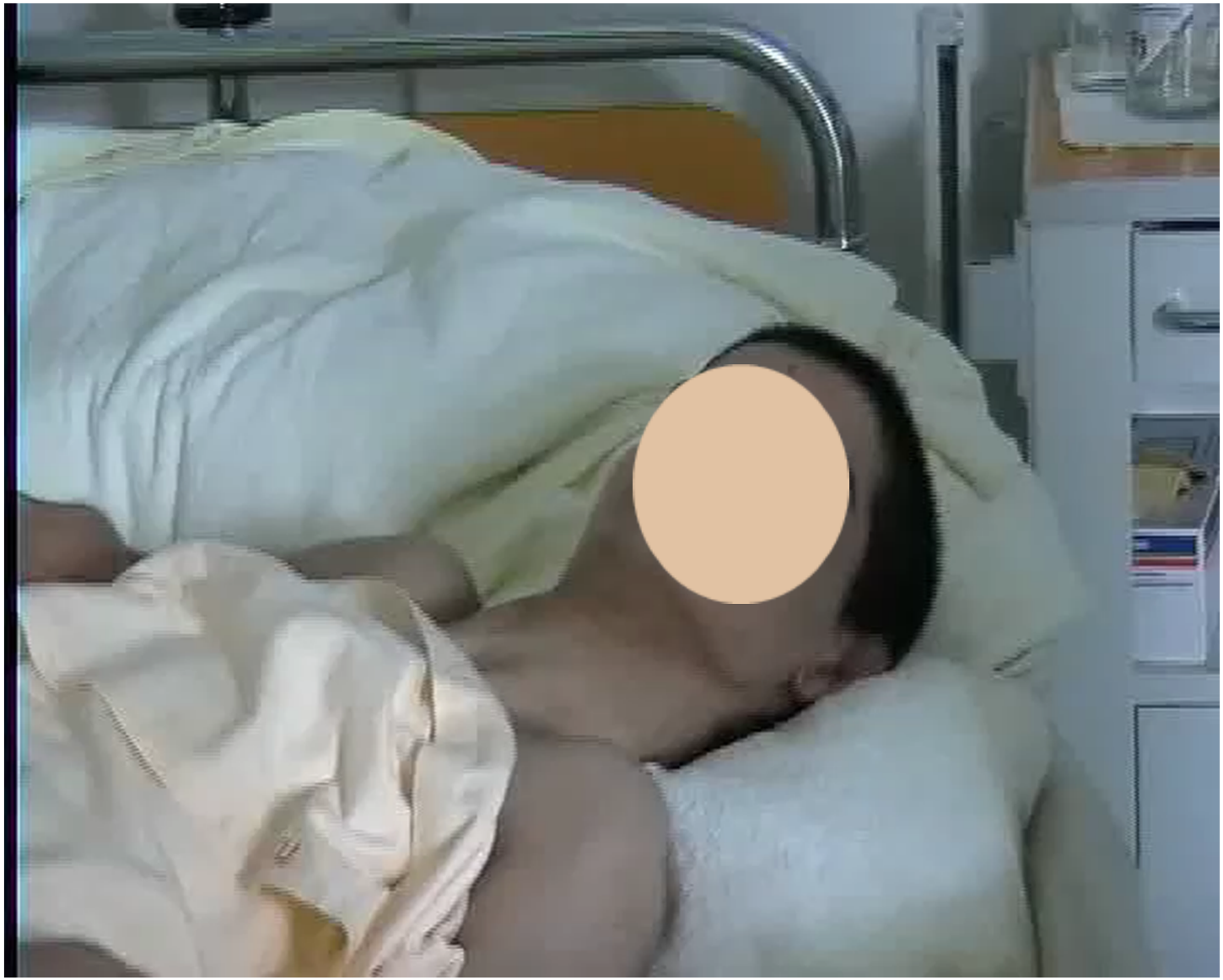



Chorea is the typically the most prominent motor feature in patients with repeat expansion in the forties (40-49) …

# … and may evolve into ballistic chorea in the course of the disease

# Bradykinesia-Dystonia – prominent in early onset HD with long repeat expansion

# Dystonia as presenting, prominent motor feature in pediatric onset dystonia



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# A first conclusion: the clinical presentation of HD depends on the size of the CAG expansion mutation

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# Natural history of HD

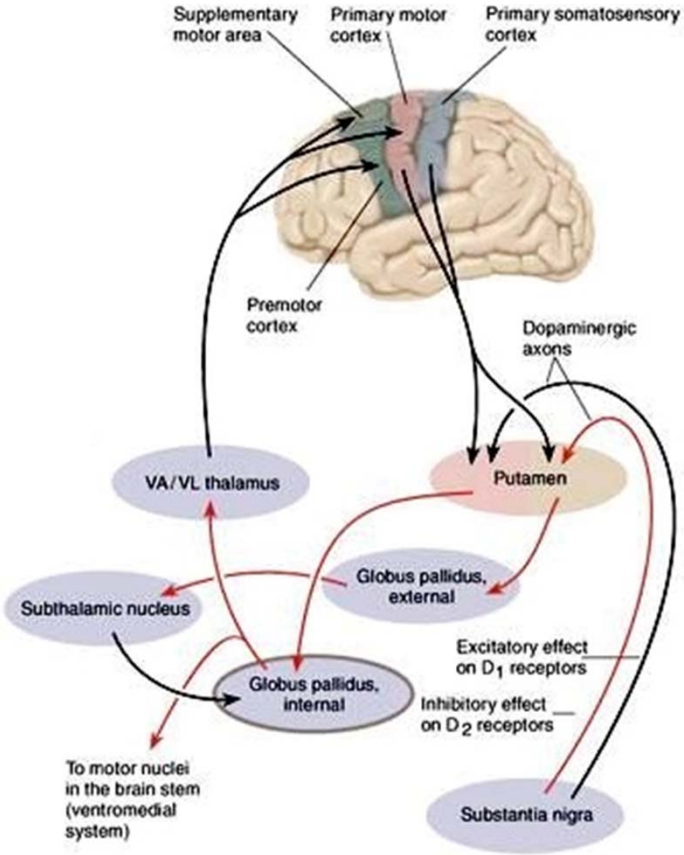
# HD is more than a movement disorder

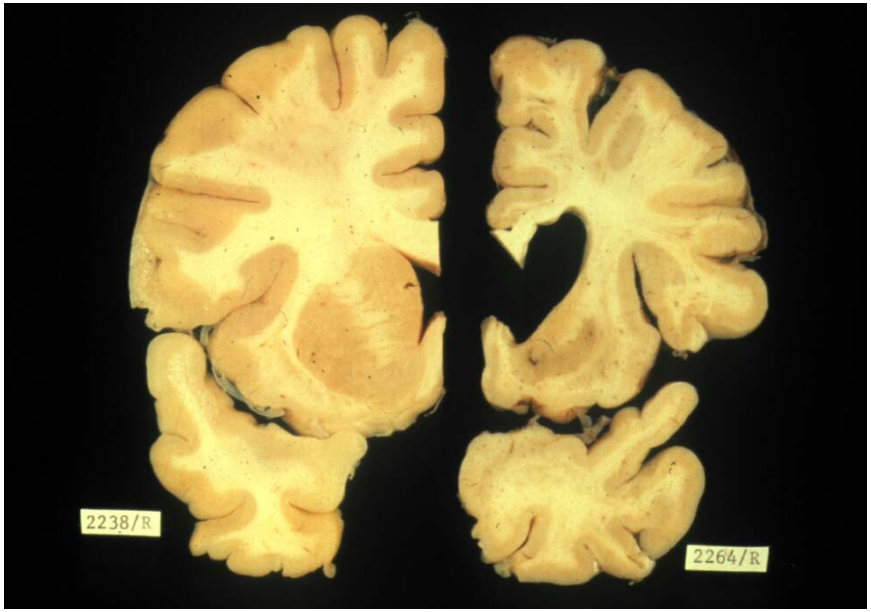
Neuropsychiatric disorder:

Personality changes

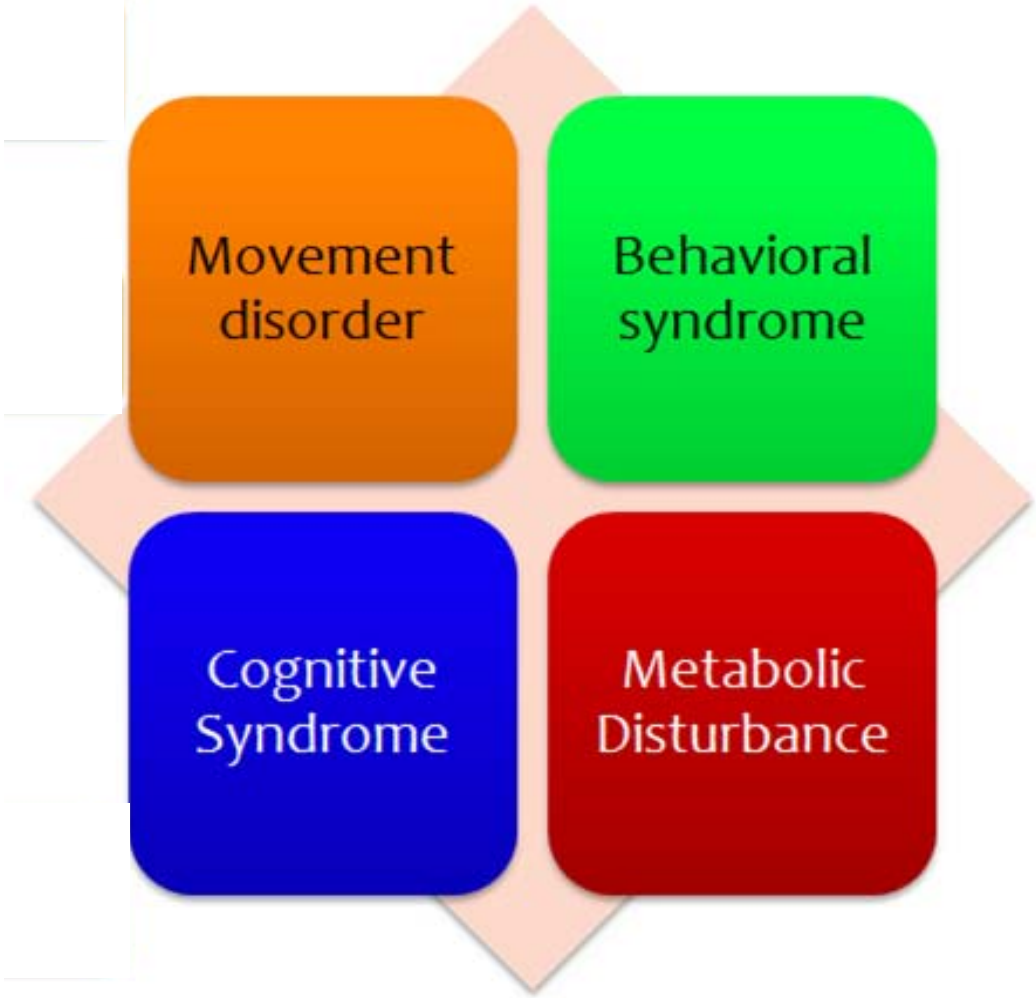
Cognitive deficits

Movement disorder



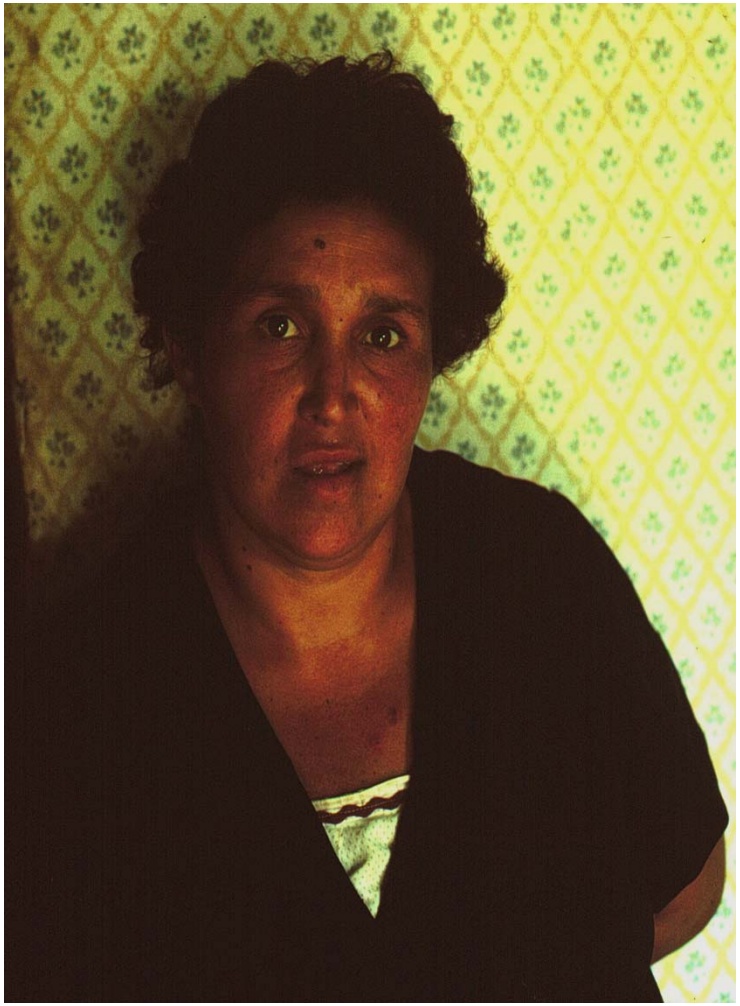



# Huntington Disease symptomatic domains



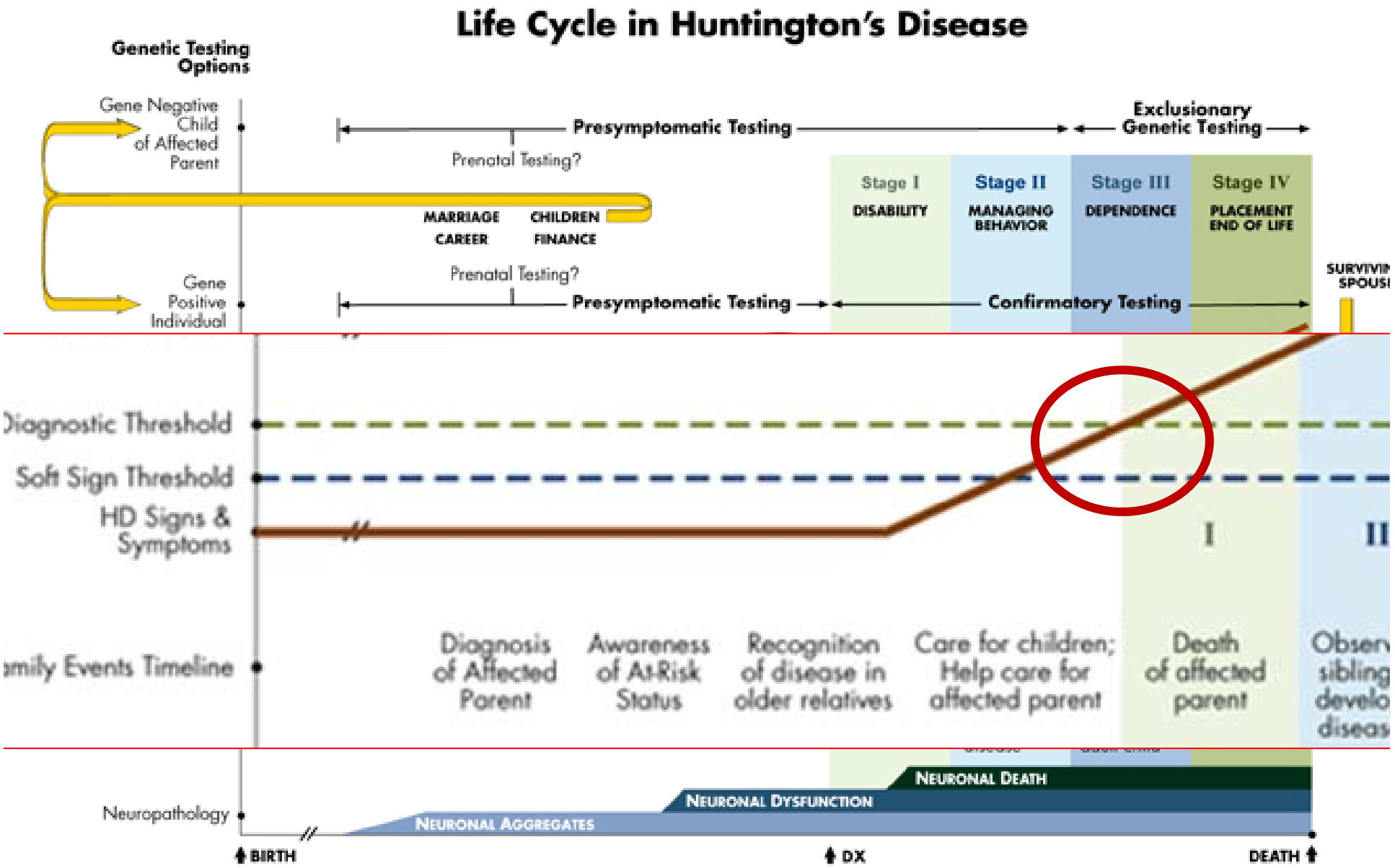
# HD is devastatingly progressive

1985



1998

# The natural history of HD: a long course




Walker FO 2007 Lancet.;369(9557):218-28

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# Insights from Large Natural History Studies

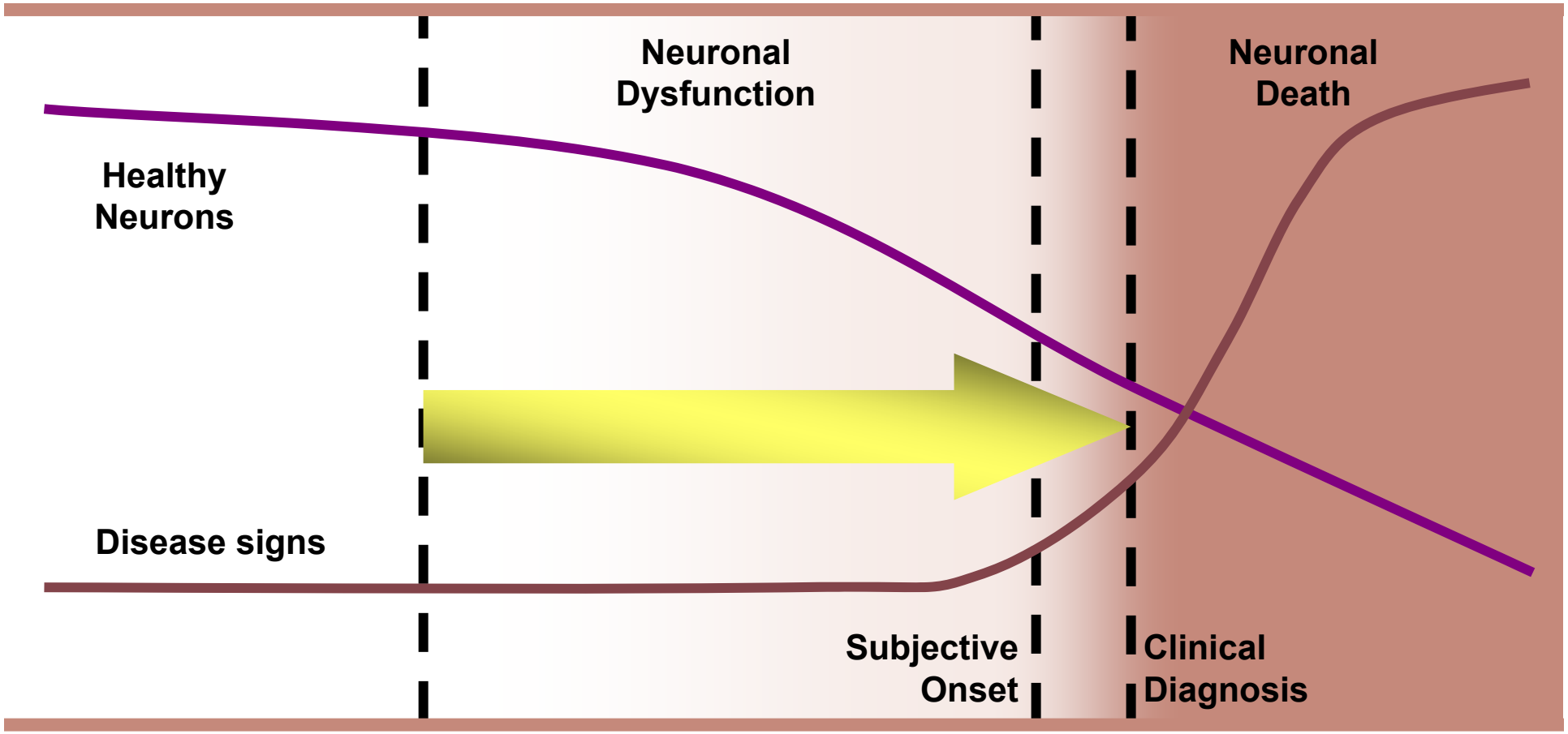

Working together worldwide to address a disease that effects people all over the world: Enroll-HD

# Enroll-HD is intended to be an enabling platform for translational and clinical HD research


- Sites: 200+
- Countries: 27
- Languages: 16
- COHORT + Registry participants: ~13,000
- Expected max. visits/month: 600
- Est. new participants/month: 200
- Globally enabled IT, bio-repository and data monitoring systems

Currently more than 25.000 participants

# HD Natural History



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# The clinically silent period: asymptomatic stages

# Looking early in HD expansion mutation carriers: trajectories

## Biological and clinical characteristics of gene carriers far from predicted onset in the Huntington's disease Young Adult Study (HD-YAS): a cross-sectional analysis

*Rachael I Scahill*, Paul Zeun*, Katherine Osborne-Crowley, Eileanoir B Johnson, Sarah Gregory, Christopher Parker, Jessica Lowe, Akshay Nair, Claire O'Callaghan, Christelle Langley, Marina Papoutsi, Peter McColgan, Carlos Estevez-Fraga, Kate Fayer, Henny Wellington, Filipe B Rodrigues, Lauren M Byrne, Amanda Heselgrave, Harpreet Hyare, Cristina Sampaio, Henrik Zetterberg, Hui Zhang, Edward J Wild, Geraint Rees, Trevor W Robbins, Barbara J Sahakian, Douglas Langbehn, Sarah J Tabrizi*

*Lancet Neurol* 2020; 19: 502–12

See Comment page 473

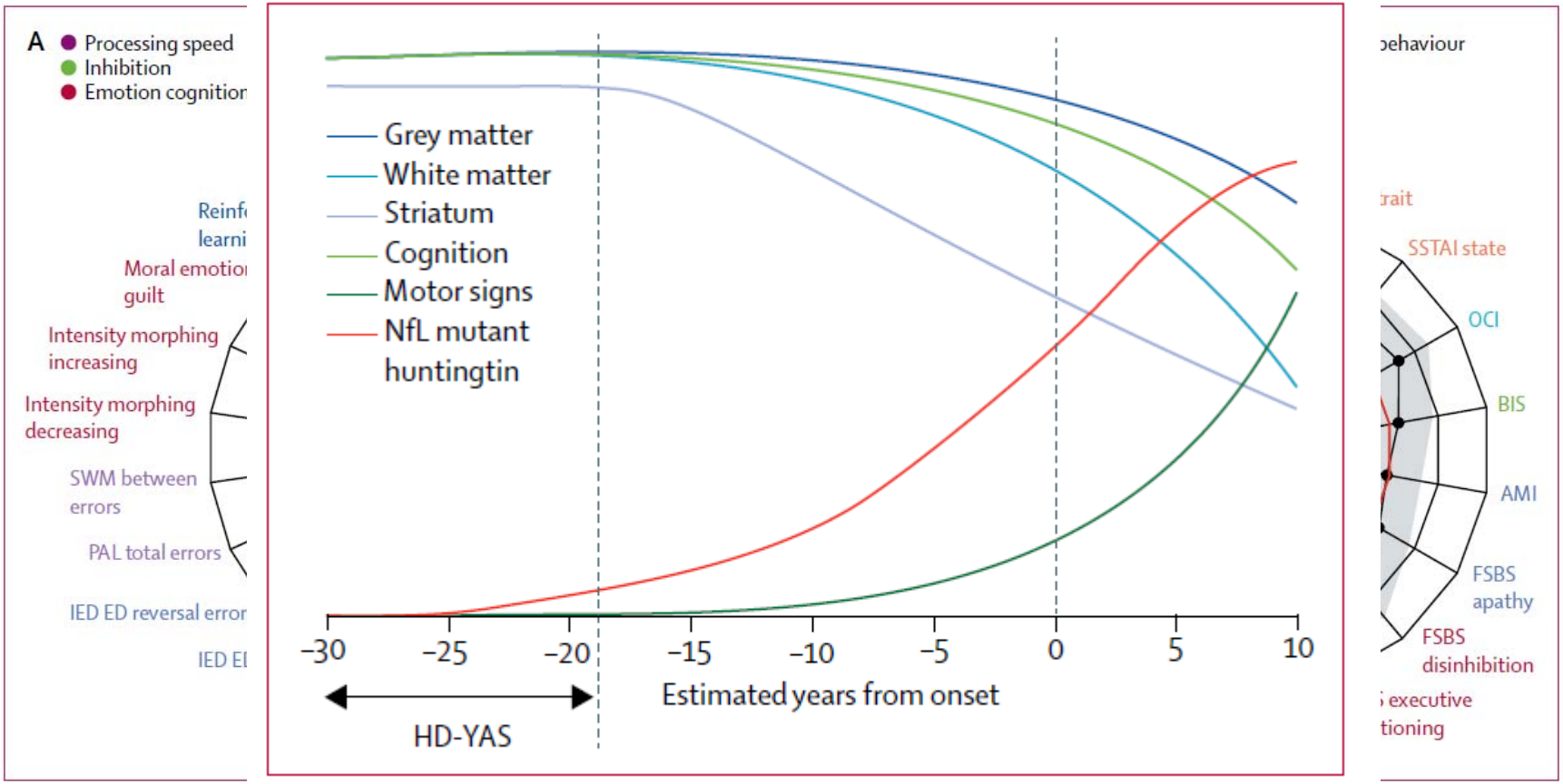
*Joint first authors

Huntington's Disease Centre,

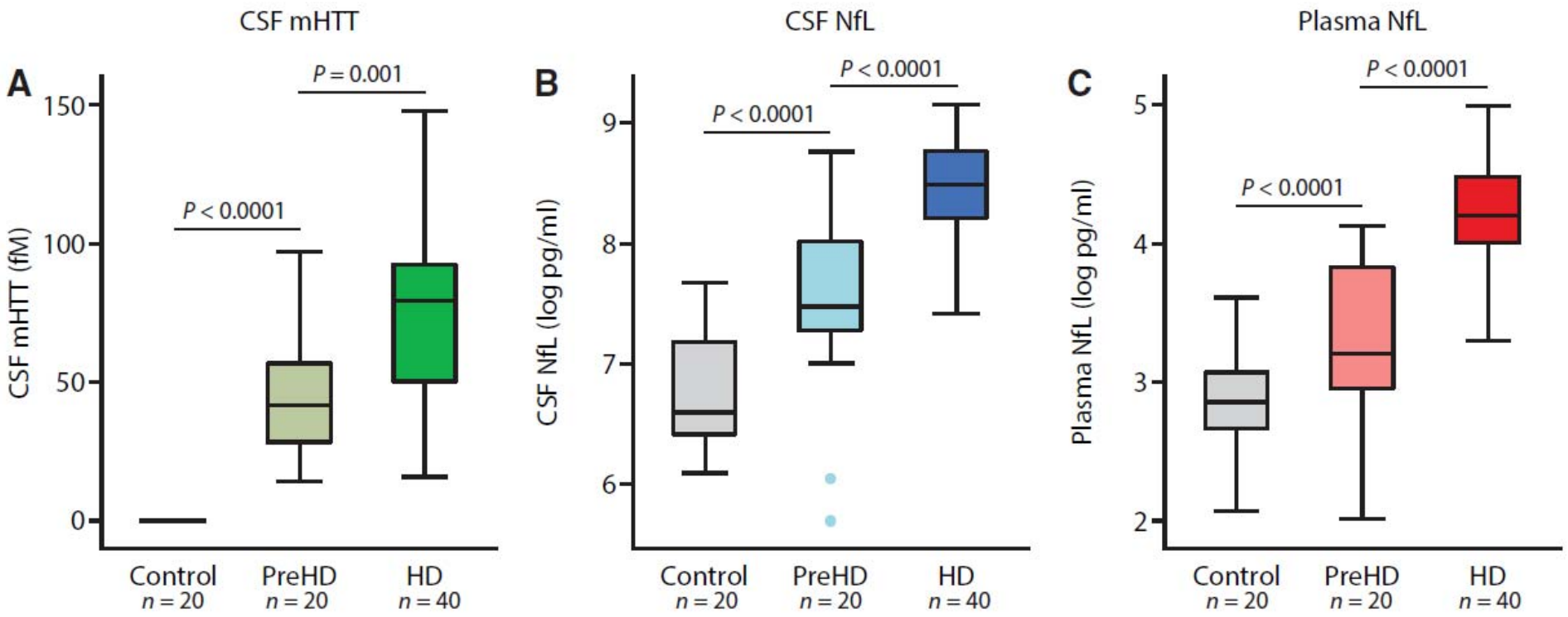
### Summary

**Background** Disease-modifying treatments are in development for Huntington's disease; crucial to their success is to identify a timepoint in a patient's life when there is a measurable biomarker of early neurodegeneration while clinical function is still intact. We aimed to identify this timepoint in a novel cohort of young adult premanifest Huntington's disease gene carriers (preHD) far from predicted clinical symptom onset.

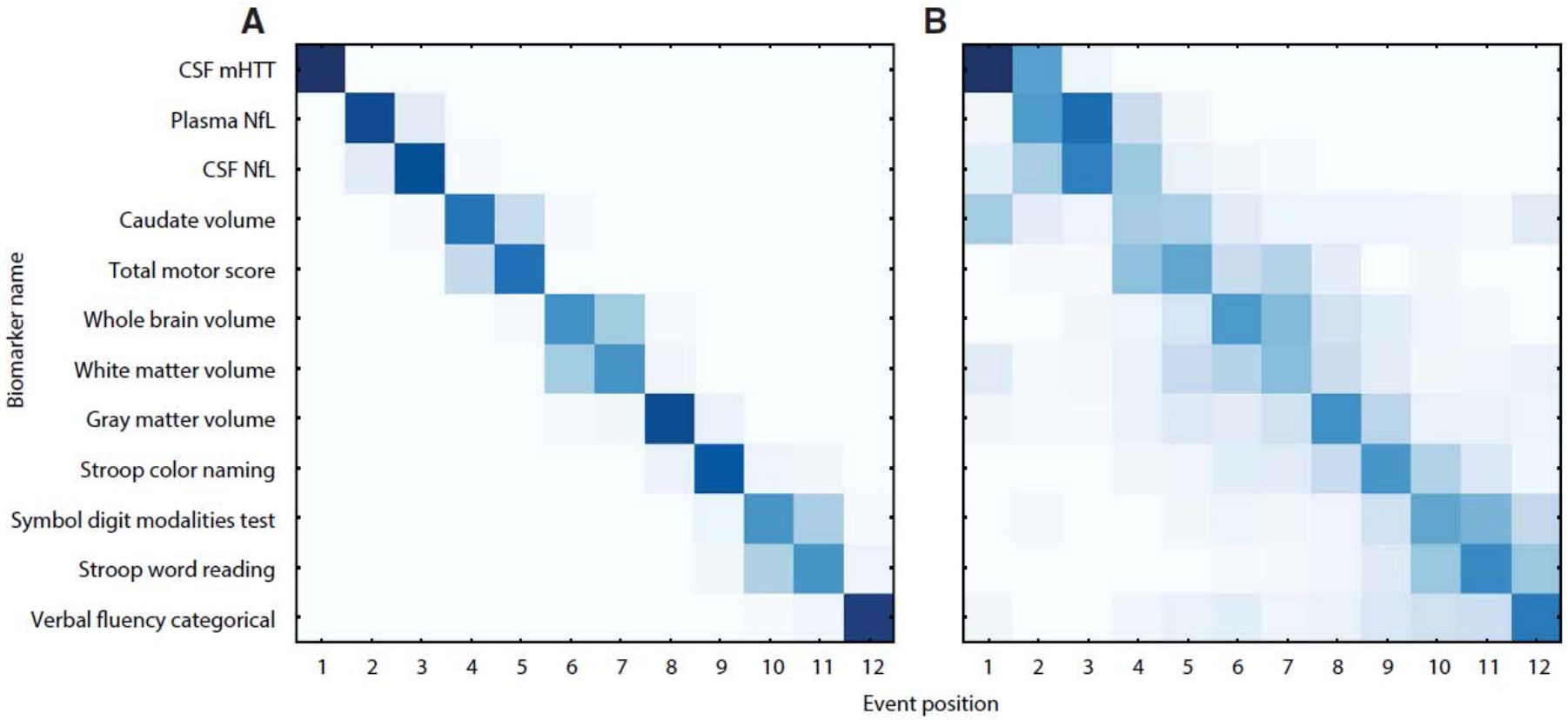
# No alterations measurable, approximately 20 years before onset, with the potential exception of NfL



# Adding wet markers



# Integrating markers & clinical signs



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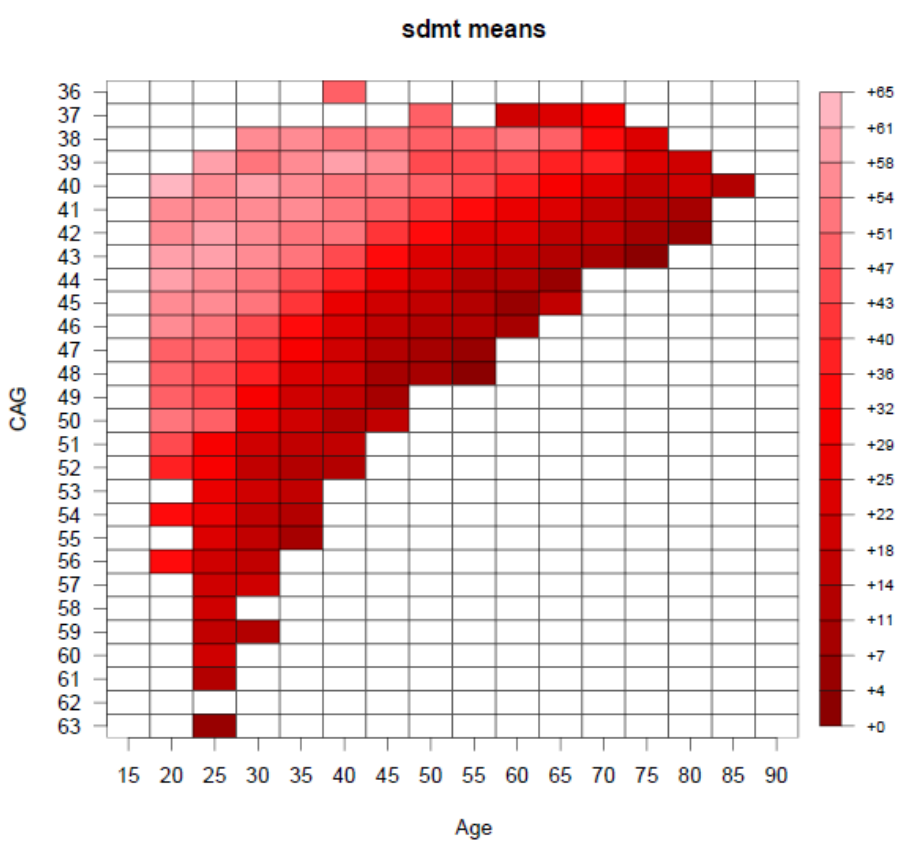
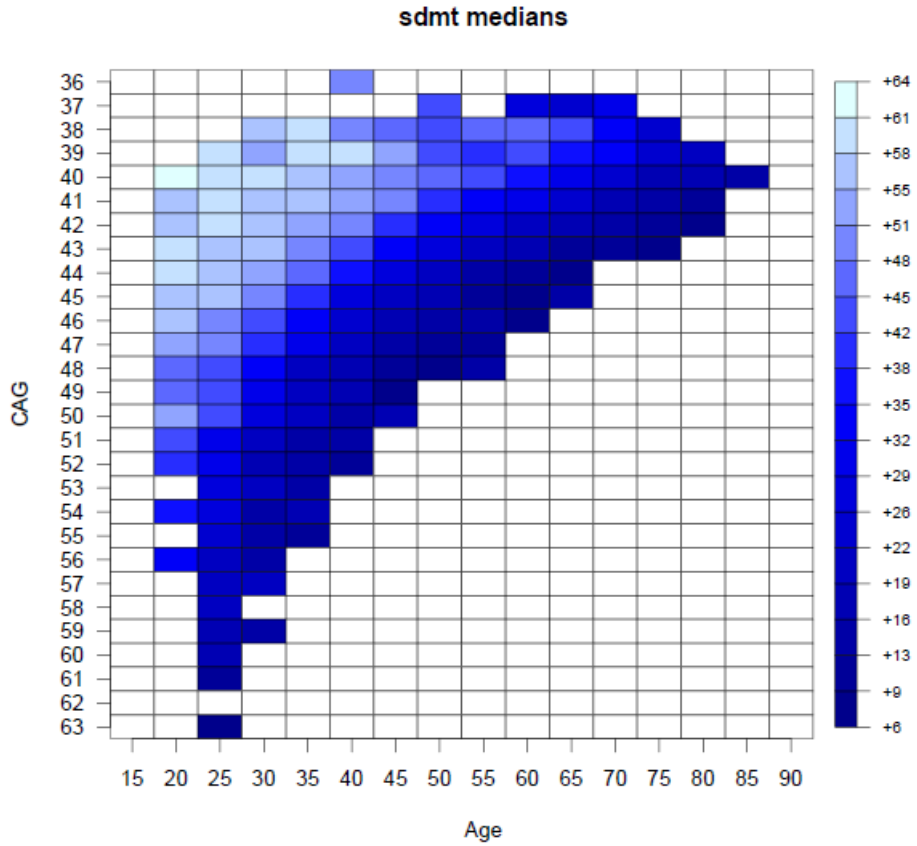
# Onset and Progression are Driven by Cumulative Exposure to Mutant huntingtin Gene Products. CAG-Length-and-Age-Product (= CAP Score) is a Measure of this Exposure.

# Modelling HD: Doug Langbehn - Age-CAG Heat Maps for each outcome



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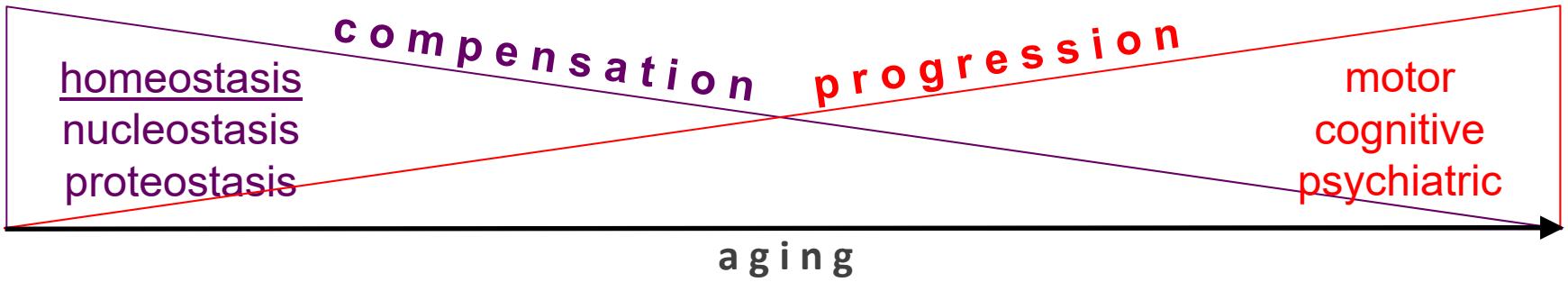
# General benefits of PT

# Compensation: what holds dysfunction in check for so long?




- Organism are intrinsically capable of compensating for the effects of mHtt gene products
- Strengthening/boosting functional reserve
- Slowing decay of homeostasis

# Activity/PT may restore balance

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# PT to ameliorate symptoms & signs of HD

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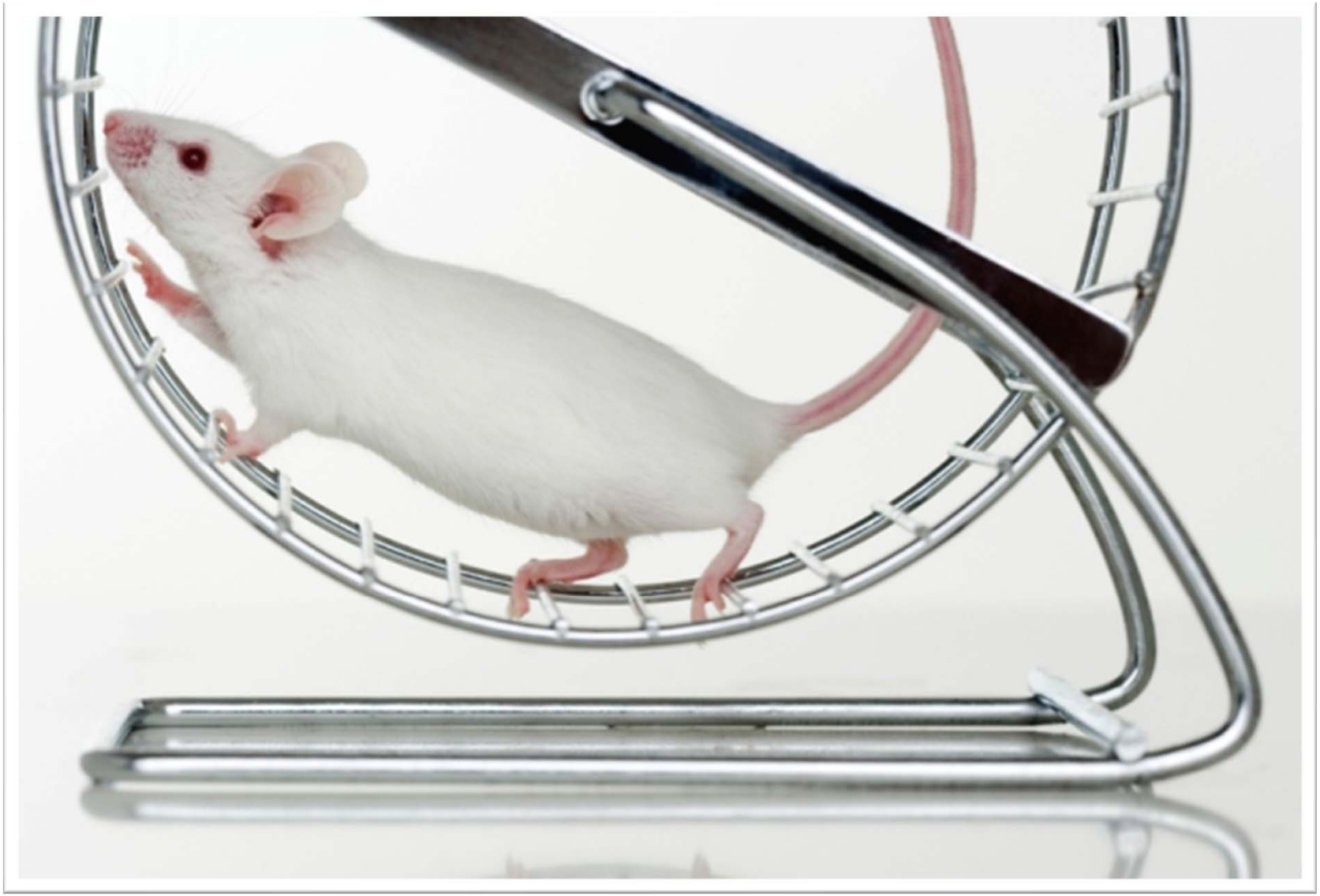
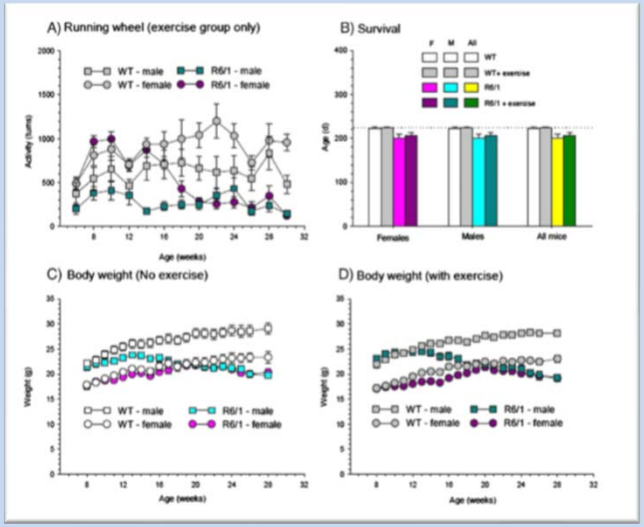
# PT as intervention to modify the course of HD?

# Preclinical studies



# Preclinical studies




**Sustained wheel running**
-> improved gait and motor coordination
-> reduced striatal neuron loss

**Six months treadmill running**
-> increaseed striatal dopamine D2 recepter expression and dopamine neurotransmitter levels
-> reduction in HTT aggregate formation
-> improved behavioral and cognitive symptoms

Harrison et al., *Experimental Neurology* 2013; Stefanko et al., *Neurobiology of Diseases* 2017

## Clinical feasibility studies & multi-disciplinary rehabilitation trials

- Busse et al., A randomized feasibility study of a 12-week community-based exercise program for people with Huntington's disease. *Journal of Neurologic Physical Therapy*. 2013
- Busse et al., A randomized feasibility study of a 12-week community-based exercise program for people with Huntington's disease. *Journal of Neurologic Physical Therapy*. 2013
- Quinn et al., Task-specific training in Huntington disease: A randomized controlled feasibility trial. *Physical Therapy*. 2014
- Quinn et al., A randomized, controlled trial of a multi-modal exercise intervention in Huntington's disease. *Parkinsonism & Related Disorders*. 2016
- Busse et al., Physical activity self-management and coaching compared to social interaction in huntington disease: Results from the ENGAGE-HD randomized, con-trolled pilot feasibility trial. *Physical Therapy*. 2017
- Thompson et al., The effects of multidisciplinary rehabilitation in patients with early-to-middle-stage Huntington's disease: A pilot study. *European Journal of Neurology*. 2013
- Piira et al., Effects of a one year intensive multidisciplinary rehabilitation program for patients with huntington's disease: A prospective intervention study. *PLoS Currents*. 2013
- Piira et al., Effects of a two-year intensive multidisciplinary rehabilitation program for patients with huntington's sisease: A prospective intervention study. *PLoS Currents*. 2014
- Ciancarelli et al., Influence of intensive multifunctional neurorehabilitation on neuronal oxidative damage in patients with Huntington's disease. Functional Neurology. 2015
- Cruickshank et al., The effect of multidisciplinary rehabilitation on brain structure and cognition in Huntington's disease: An exploratory study. Brain and Behavior. 2015

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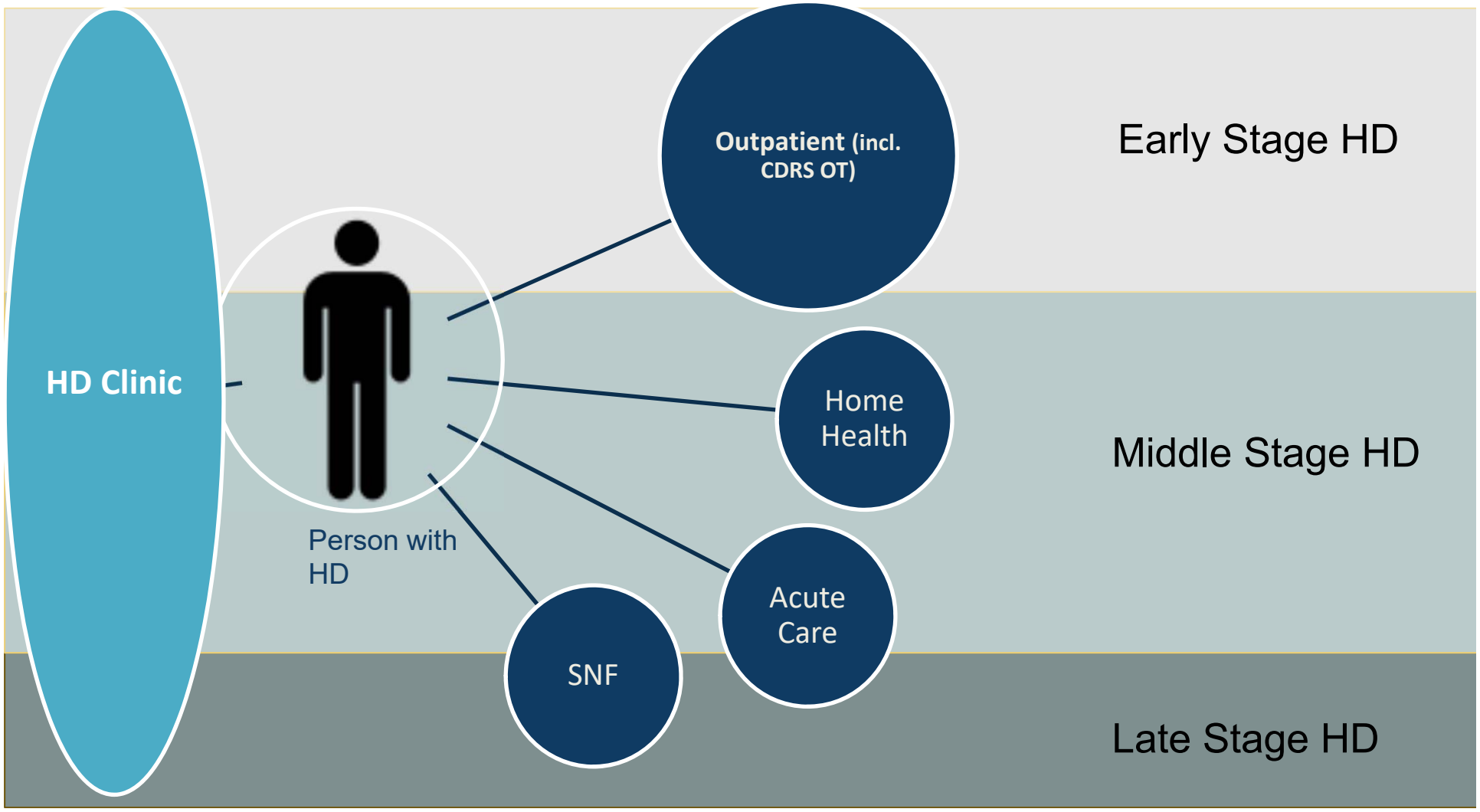
# PT as intervention to modify the course of HD – rehabilitation

# Rehabilitation Over the Course of the Disease



# Literature

- Target groups: Early- to mid-stage HD
- Observational studies indicate positive effects of multidisciplinary rehabilitation on physical function/balance, swallowing, independence, mood and social relationships

  (Zinzi et al, Clin Rehab 2007; Ciancarelli et al, Eur J Phys Rehabil Med, 2013; Thompson et al Eur J Neurol 2013)
- A randomized study of a 12-week community based program found that the program was safe, feasible, acceptable and suggests beneficial effects of rehabilitation

  (Busse et al, JNPT, 2013)

# The Norwegian Project: Jan Frich et al

- Intensive rehabilitation programs for patients with HD was funded by the Norwegian Directorate of Health in 2009
- The initiative was inspired by the results from a landmark observational study (Zinzi et al, Clin Rehab, 2007)
- The aim of the mixed-method evaluation was to assess the feasibility and the effects of participating in a one-year multidisciplinary rehabilitation program

Ethical approval by Norwegian Social Science Data Services (ref. 26587) and The Regional Ethics Committee, Health Region South-East (ref. 2010/1026-1)

# One year program: 3 x 3 weeks stay + evaluation stay

**Stay 1 (3 weeks)** → **Stay 2 (3 weeks)** → **Stay 3 (3 weeks)**

↓

**Evaluation stay 3 months (95.4 days (SD ±34.2) after discharge of the last stay**

Tromsø

Vikersund

**Start of each stay**

Cognitive function (MSSE), depression (HADS), motor function, balance, gait (ABC, 6 Min. Walk Test …) ADL (Barthel)

**End of each stay**

Motor function, balance, gait

**Three weeks stay**

- 8 hours of various activities 5 days a week
- Groups of 4-6
- Physiotherapy / exercise
- Group meetings, trips, making food, etc

3 months …

# The multidisciplinary team

- Physician/neurologist
- Nurses
- Physical therapist
- Occupational therapist
- Speech therapist
- Dietician
- Social worker
- Psychologist

- The institutions are specialised regional rehabilitation centres (stroke rehabilitation etc.)

# Main findings

- Significant improvements were observed in gait function, balance, in physical quality of life, anxiety and depression, as well as in BMI
- ADL-function remained stable with no significant decline
- One cognitive measure (SDMT) showed significant decline, while no decline was observed for the remaining cognitive measures

Piira A, et al PLOS Curr 2013

EUROPEAN **HUNTINGTON'S DISEASE** NETWORK

# PT as intervention to modify the course of HD – delaying onset, slowing progression?

# PACE-HD

Physical ACtivity and Exercise Outcomes in Huntington's Disease, Phase II

1:1 randomisierte kontrollierte Interventions-Studie

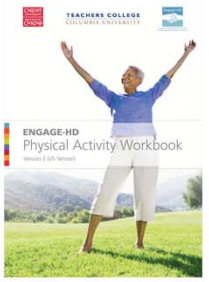
Activity as usual

Physical therapy and exercise intervention including wearables

12 Monate

Quinn et al., *Handbook of Clinical Neurology* 2017

# PACE-HD



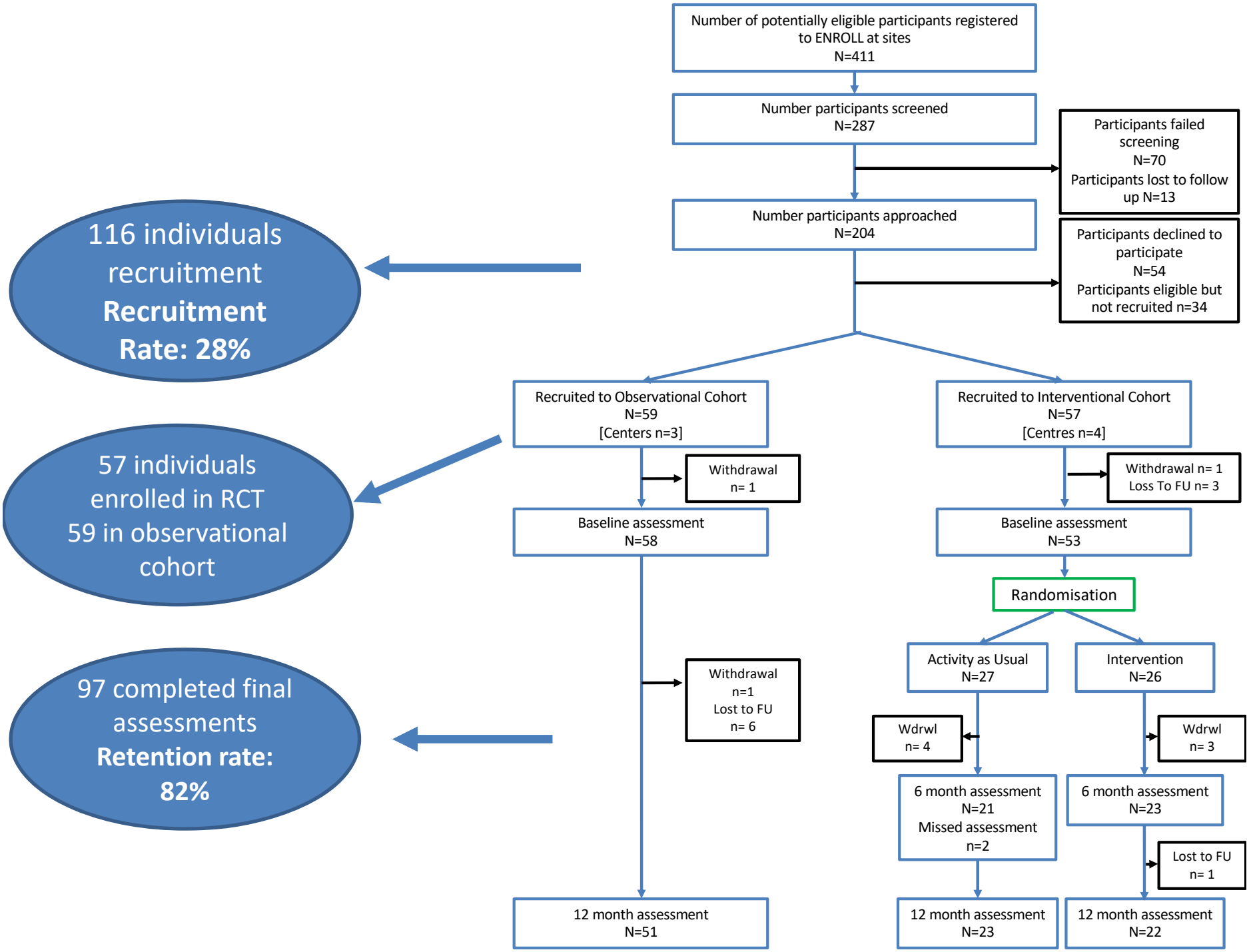

## AIMS

1. To establish feasibility of a within cohort nested randomised trial of a 12-month physical activity intervention in people with HD

2. To explore effect estimates for physical activity, endurance, disease-specific motor function of long term (12 months) exercise in HD compared to usual activity.

Multi-center trial conducted in Europe and US

- UCLA/Columbia/Merce/FJD/Ulm/Aachen/GHI
- Individuals with early-mid stage HD
- Trial within Cohort –linked with Enroll


Number of potentially eligible participants registered to ENROLL at sites
N=411
Number participants screened
N=287
Participants failed screening
N=70
Participants lost to follow up N=13
Number participants approached
N=204
Participants declined to participate
N=54
Participants eligible but not recruited n=34
116 individuals recruitment
Recruitment Rate: 28%
Recruited to Observational Cohort
N=59
[Centers n=3]
Recruited to Interventional Cohort
N=57
[Centres n=4]
57 individuals enrolled in RCT
59 in observational cohort
Withdrawal
n= 1
Withdrawal n= 1
Loss To FU n= 3
Baseline assessment
N=58
Baseline assessment
N=53
Randomisation
97 completed final assessments
Retention rate: 82%
Withdrawal
n=1
Lost to FU
n= 6
Activity as Usual
N=27
Intervention
N=26
Wdrwl
n= 4
Wdrwl
n= 3
6 month assessment
N=21
Missed assessment
n=2
6 month assessment
N=23
Lost to FU
n= 1
12 month assessment
N=51
12 month assessment
N=23
12 month assessment
N=22

# Pace-HD: Outcome Measures

## Construct

- Fitness
- Walking endurance
- Physical activity

## Measure

- Predicted VO2 max cycle ergometry
- 6 minute walk test
- Questionnaire (IPAQ)

GeneActiv accelerometers


Enroll-HD

# PACE-HD Intervention

- **1:1 Physical therapy sessions** focusing on increasing physical activity at home

- **Choice of equipment** or funds to support community engagement


- **Fitbit devices** for all participants to track activity and monitor goals


- **HD-specific exercise workbook** to support education and goal-setting

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Study is completed
Result is eagerly awaited

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# Long-term clinical rate-of-progression studies are needed

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# Biomarker based studies (e.g. NfL, BDNF etc.) are needed

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# Challenges ahead

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# Defining who to treat when

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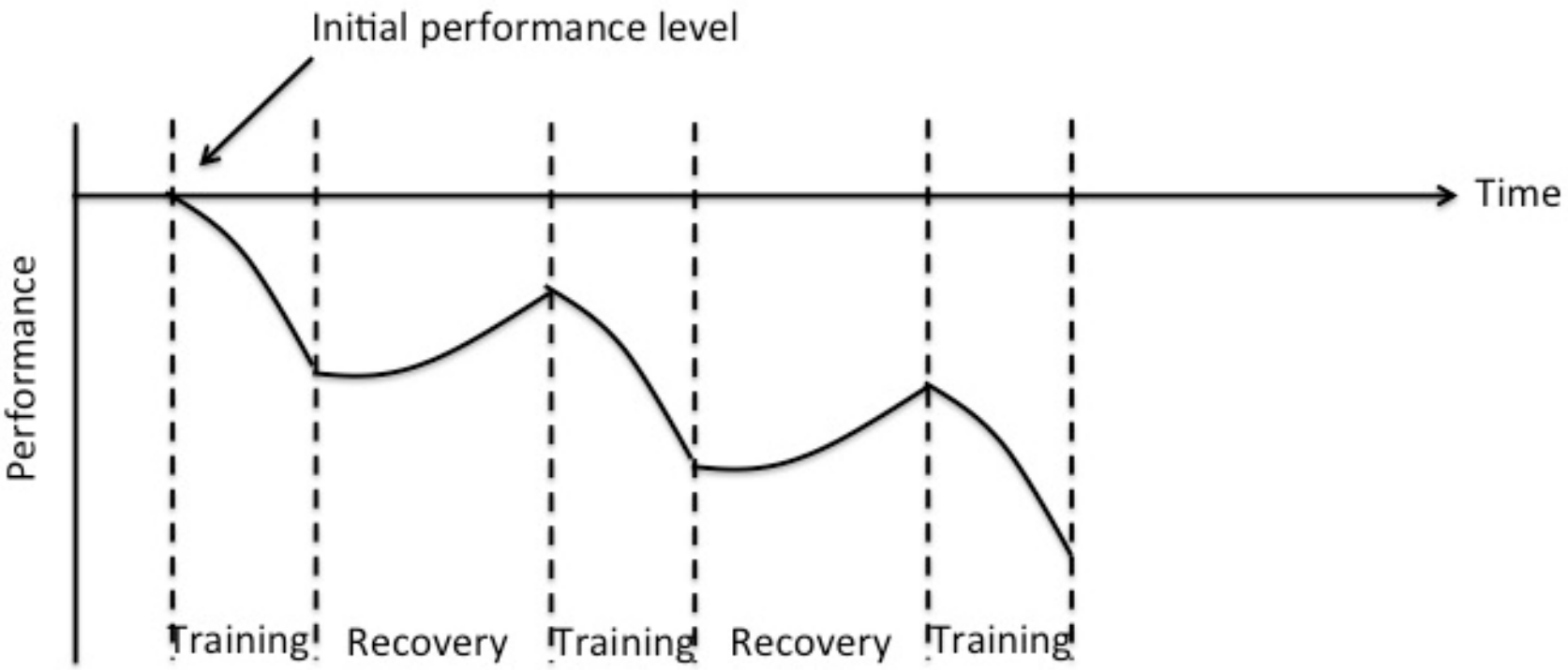
# Defining the intervention

# Defining dose




**Model of overtraining: Training load followed by insufficient recovery results in decreased performance.**

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# Defining outcome measures

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# Practical challenges in implementing PT

**Facilitators**

*Identification of facilitators of participation in exercise for persons with HD*

*Personal Factors*

- Self efficacy of the participant and his/her outcome expectations (34)

*External Environmental Factors*

- Identification and commitment of the caregiver/contact person (34, 34)

*Training Factors*

- Individualized plans and schedules (33)
- Intensive training is acceptable (33)
- Being part of a group is helpful (33)
- Cues provided by an exercise DVD helps with adherence (34)

Fritz et al (2017). *Physical Therapy and Exercise in Huntington's Disease Systematic Review*

## Barriers

*Identification of barriers to participation in exercise for persons with HD*

*Personal factors*

- Cognitive impairment (33, 34)
- Physical factors (e.g. poor balance) (34)
- Lack of motivation (34)

Fritz et al., *Physical Therapy and Exercise in Huntington‘s Disease Systematic Review* 2017

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# Apathy

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# Participant fatigue

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# Caregiver fatigue

# The Golden Age of Telehealth Is Here (Thanks to the Coronavirus)

**Mar 17th, 2020** 3 min read


Marie Fishpaw

**Director, Domestic Policy Studies**

*Marie Fishpaw is Director of Domestic Policy Studies at The Heritage Foundation.*

EUROPEAN **HUNTINGTON'S DISEASE** NETWORK

# The situation may be shit, but it's our fertilizer for the future

Lennart Georg Meri
President of Estonia, 1992 to 2001

From the in-clinic interview, it might sound like this …

On telehealth, the reality may be visible…

Seeing the **reality** is better for making more appropriate, realistic recommendations

# HEALTHE –RND

## European eHealth Care Model for Rare Neurodegenerative Diseases

JPND research
EU Joint Programme – Neurodegenerative Disease Research

EHDN EUROPEAN HUNTINGTON'S DISEASE NETWORK
*Advancing Research, Conducting Trials, Improving Care*

Enroll-HD

**HD-Needs**
- Development of Need-Based Quality of Life(QoL) Questionnaires
- HDEMCs and Caregivers
- Three stages

**HD-eHelp**
- Development of e-Health Care Platform with Users involved in all stages
- Multilingual and -disciplinary
- Three stages

**HD-Proof**
- Evaluation of e-Health Care Platform
- Proof of Concept Study (POC)
- e-Health Intervention vs. Treatment As Usual (TAU)
- Primary Outcome: Need-Based QoL
- Secondary Outcomes: effects for short (3 M), intermediate (6 M) and long term (12 M) exposure to the e-health care vs. TAU

Institutional Logo,
‚Speakers' picture or
disease related picture

# Key Points /Conclusions

- There is evidence that PT has a beneficial impact for people affected by HD with respect to symptom relief and short-term improvement in most stages HD
- There is currently a lack of evidence for long-term impact and the potential of PT to modify the natural course of HD, in particular in pre-manifest/early stages of HD, dependent on novel assessment tools, e.g. biomarkers
- Telemedicine offers new avenues to deliver PT and to assess real life impact/benefit

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- People affected by HD and their partners & caregivers


EHDN EUROPEAN HUNTINGTON'S DISEASE NETWORK
*Advancing Research, Conducting Trials, Improving Care*

HUNTINGTON STUDY GROUP
seeking treatments that make a difference

Jacques & Gloria Gossweiler Foundation

# Thank you for your attention!

G. Bernhard Landwehrmeyer

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Network Neurological Diseases (ERN-RND)

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Network Neuromuscular Diseases (ERN EURO-NMD)

**DG ‚Chorea and HD'**
**20. October 2020**

European Reference Network | Neurological Diseases (ERN-RND)

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# Joint webinar series

# THANK YOU

Next Webinar: **‚Non-invasive stimulation for ataxias'**

**by Bart van de Warrenburg**

3. November 2020, 15-16h CET