

Christine Capper-Loup<sup>1,2</sup> and Michael Orth<sup>1,2,3</sup>, on behalf of EHDN

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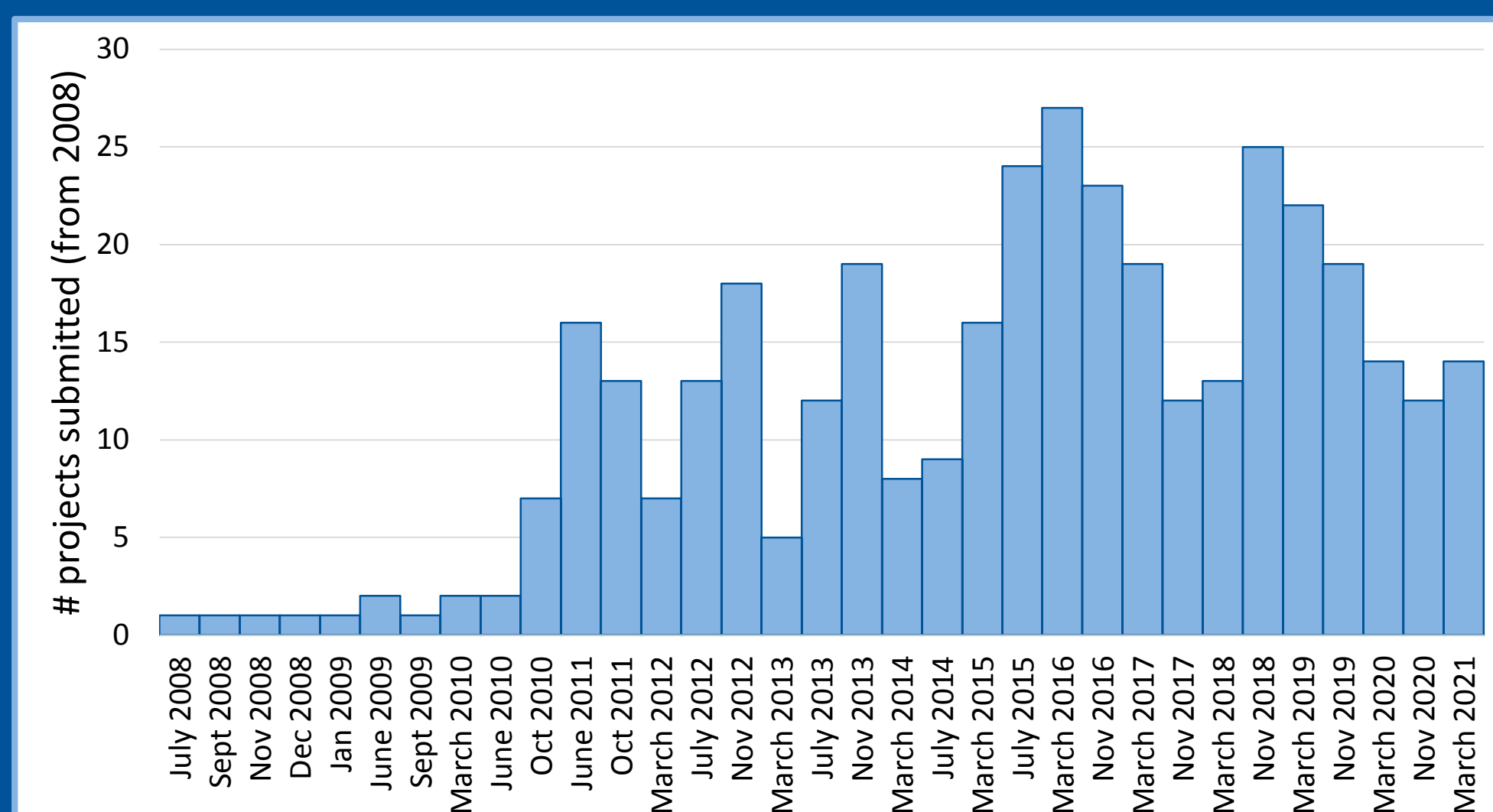
The European Huntington's Disease Network (EHDN) is an independent non-profit organisation dedicated to advancing research, conducting clinical trials and improving care for people affected by Huntington's disease (HD). In order to advance research, EHDN has developed a number of strategies that are described below.

For strategies on conducting clinical trials and improving HD care, see EHDN poster

## Seed Funds

- To help generate pilot data before applying for larger grants.
- To conduct power calculations for clinical studies.
- Two calls per year; deadlines on 1 March and 1 November.
- The maximum sum available is EUR 50,000.
- Reviews done by the Scientific and Bioethics Advisory Committee (SBAC), decisions taken by the Executive Committee (EC).

Visit <http://www.euro-hd.net/html/projects/proposals/seedfund>



Number of projects submitted at each deadline from 2008. From 2011, the minimum number of projects received was five (on March 2013) with a peak of 27 (March 2016). In total, 379 projects were submitted; 81 of them have been approved for funding.

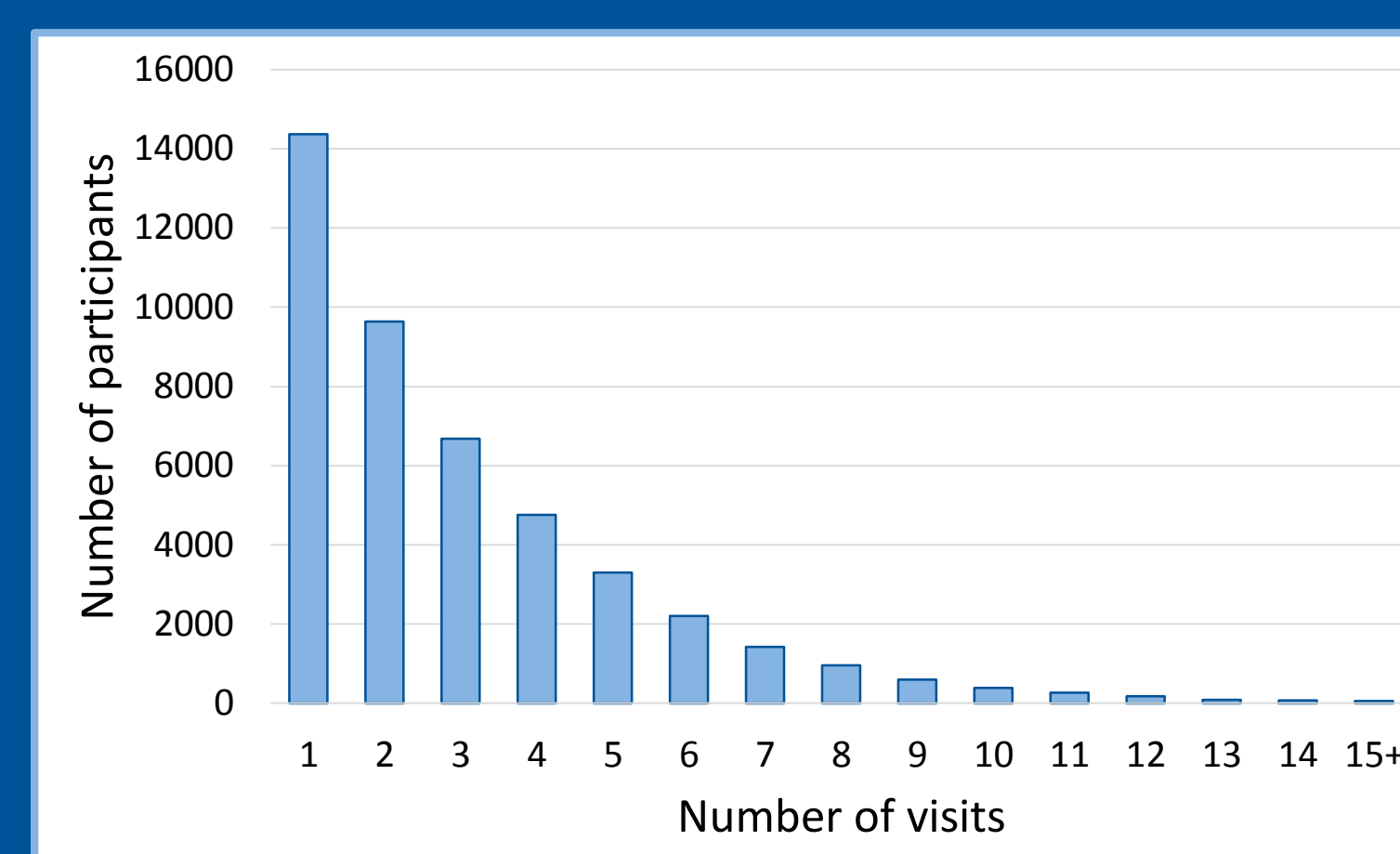
Based on the follow-up information received:

- 56 of the 81 funded projects completed (mostly within 12 months).
- 58 publications (on average three years after approval).
- Total funding for all seed fund projects to date is ~ EUR 2.8 million, more than EUR 11 million generated using seed fund data.

## Registry Data and Biosamples



- Registry: EHDN non-interventional study, mapping the natural course of HD, active from 2004 to 2017.
- Observational, prospective, longitudinal, multi-national, multi-centre cohort study of HD on individuals at risk, premanifest, manifest for HD and age and gender-matched control participants.
- 153 data mining applications received, with 66 publications.
- Registry dataset (RDS): released in 2019, contains data from >14,000 participants across 17 European countries and > 150 sites.
- Biospecimens: DNA (from cell lines or from blood), cell lines, PBMC.



Frequency plot of number of REGISTRY RDS. This plot is cumulative; participants with data from more than 1 visit will be represented in multiple columns (a participant with data from 3 visits would be represented in columns displayed for 1, 2 and 3 visits).

- RDS format similar to the Enroll-HD periodic datasets (PDS).
- RDS and Enroll-HD PDS use the same recoded IDs.
- A subset of the RDS data is included in the Enroll-HD PDS for participants who have transitioned; however, there is a wealth of Registry data that are unique to the RDS.

## Think Tank

- Complements and facilitates EHDN research initiatives such as the Working Groups (WG) or Task Forces (TF). TF is a temporary grouping for the purpose of accomplishing a defined objective.
- Interacts with WG and TF lead facilitators to help identify potential collaborators or funding opportunities for their research, or to discuss scientific ideas.
- Identifies key scientific questions in HD, some of which could be addressed scientifically by HD researchers through existing or new WGs or TFs.

Visit <http://www.ehdn.org/about-ehdn/hd-science-think-tank/>

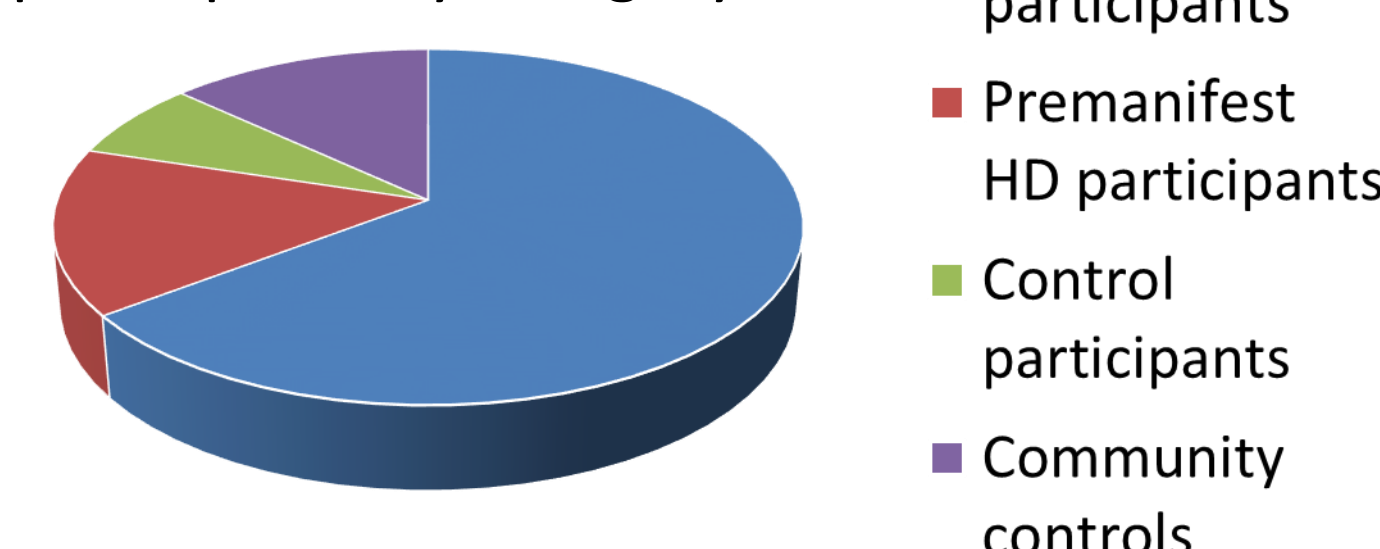
<http://www.ehdn.org/about-ehdn/ehdn-working-groups/>

Name of the group	Lead Facilitators
<b>Working Groups</b>	
Advanced Therapies	William Gray, Romina Aron-Badin
Behavioural Phenotype	Jenny de Souza
Biomarkers	Niels Skotte, Ed Wild
Cognitive Phenotype	Jaime Kulisevsky, Saül Martinez-Horta
Genetic Modifiers	Tom Massey, Hoa Nguyen
Genetic counselling and testing	Rhona MacLeod, Nayana Lahiri
Health Economics	Hugh Rickards
Imaging	Rachael Scahill, Nicola Hobbs
Motor phenotype	Ralf Reilmann, Raymund Roos
Multidisciplinary treatment and care	Marleen van Walssem, Ruth Veenhuizen, Astri Arnesen
Paediatric HD	Oliver Quarrell
Physiotherapy	Una Jones, Deb Kegelmeyer, Anne Kloos
Psychological Interventions	Maria Dale, Jane Simpson
Quality of Life	Aileen Ho, Bea de Schepper
Systems modeling	Christian Neri, Juan Botas
Young Adults	Peter Carruthers, Catherine Martin, Chandler Swope
<b>Task Forces</b>	
Fitness to drive	Rients Huitema
HEATED	Hugh Rickards
Incidental Findings	Hoa Nguyen, Nayana Lahiri
Dysphagia	Christina Lang, Angela Nuzzi

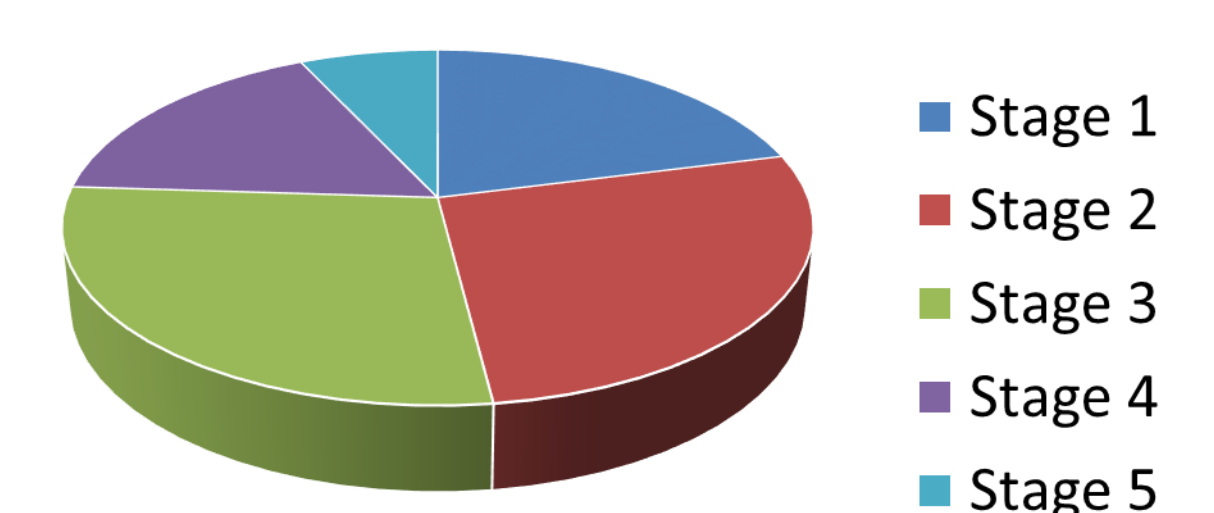
Another new group is currently in development: the Digital Assessments WG, led by Marcus D'Souza.

Working group coordinator: [kristina.becanovic@euro-hd.net](mailto:kristina.becanovic@euro-hd.net)

Percentage of Registry participants by category



Percentage of manifest HD participants by disease stage



- Information on how to apply, including the costs of sample preparation and shipment can be found on the following webpage: <http://www.euro-hd.net/html/projects/proposals/scipro>
- Access to the RDS and renewable biosamples involves a review of the project by the Chairs of the EHDN SBAC and EC.
- Access to data not provided in the RDS can be applied for via a specified dataset request. An application for obtaining access to specified dataset or non-renewable biosamples will undergo full review by the SBAC and EC.

## Grant management and collaborations

- The EHDN Grant and collaborations manager ([fionnuala.margreiter@euro-hd.net](mailto:fionnuala.margreiter@euro-hd.net)) can support HD researchers in identifying potential funding opportunities and collaborations.
- Information on current funding opportunities can be found at: <http://www.ehdn.org/hd-clinicians-researchers/grant-manager/>

See EHDN poster for additional information on the EHDN/MDS-ES Virtual HD Course Series and Joint Fellowship Exchange Programme