Strategic plan 2023-2028

Background

The first strategic plan covered the period 2011-2015, provided detail on the mission, aims and objectives of EHDN and set out a strategy to work towards achieving these aims. The plan was revisited at the end of this period and a revised plan generated for 2017-2021, which included some critical areas of reorganisation, optimisation and proposed some new initiatives such as establishing the scientific think tank to better support working groups and facilitate the delivery of EC decisions, the creation of task forces as a mechanism to deliver key strategic scientific priorities, and development of a communication plan, much of which has been successfully implemented.

The previous plans envisaged further period revisions of EHDN strategy and this document presents a revised plan for the period 2023-2028. The strategic plan writing group comprised the EHDN chair and co-chairs, the SBAC co-chair, one EC member, the EC EHA representative and the EHDN science manager. The committee met remotely on a regular basis for discussion. The strategic plan writing group undertook an analysis of the previous plan to assess successes, lessons learned and identify threats and opportunities as a first step in generating a new plan. The development of the plan has been an iterative process following discussion with the EC. The intention of the plan is to provide guidance and to stimulate further growth and development of EHDN, taking into consideration the developments in the HD field, rather than to provide a rigid road map

Over the last 5 years, some key changes relevant to this plan have occurred. In particular:

- there has been continued development of new strategies for treating HD;
- clinical trials have progressed and there are now a number of disease-modifying trials of complex advanced therapies in progress; these trials are beginning to yield results which are often complex
- the first phase 3 study of a potential disease modifier (huntingtin lowering) had to be discontinued prematurely, and since then a further early phase trial has been discontinued. The field has already learned many lessons from this, but continuing to provide mechanisms for facilitating such learning is important;

- the covid-19 pandemic disrupted many elements of EHDN activity, but has also allowed us to learn some important lessons about our operational processes that have impacted this strategy;
- the urgency of the climate change crisis has heightened and has relevance to every element of our lives, and therefore needs to be taken into account.

The impact of these factors will be seen in throughout the new plan.

EHDN mission and previous Strategic plans

EHDN founding mission is to improve the lives of people from HD families. In order to achieve this, its key objectives are to advance research, conduct clinical trials and improve care. While we can separate these strategies in pursuing the EHDN's overall mission, it is important to bear in mind how closely connected they are. For example, the anticipated outcome of research will be new interventions for treatment and new tools for measuring their efficacy, both in trials and in clinical practice. However, without the ability to test new interventions in clinical trials, such research would not be translated into new treatments for HD patients, and equally, the best preparation for clinical trials would be wasted if research did not generate new compounds to test.

The first strategic plan in 2011 set out nine objectives which formulated scientific ambitions and provided clarity on the structural organization necessary to achieve them, including detailed elements of scientific governance, such as the creation of a research managers post and hiring of a medical writer, designation of a study coordinator from the EHDN staff for every project, refocusing the objectives of all active groups (mainly WGs) in accordance with EHDN´s main mission and set out ambitions such as stimulating research funding, stimulating scientific collaboration, improving training, and improving communication. The nine objectives remain pertinent to achieving EHDN mission and are to:

- improve HD patients' health outcomes
- improve the design of good-quality clinical trials
- expedite conclusive clinical trials
- enhance the understanding of the progressive phenotypic spectrum of the disease
- enhance the development of efficacious treatments (both pharmacological and non-pharmacological)
- enhance the understanding of the disease mechanisms
- facilitate transfer of scientific evidence to clinical practice
- improve HD family members' health outcomes
- increase knowledge and recognition of EHDN as an European research network**.**

The second strategic plan was intended to cover the period 2017-2021. The planned revision of the strategy was delayed in the pandemic recovery, and so this plan has continued to operate throughout 2022. The subgroup that drove the writing of this second plan started with a detailed analysis of the first plan, concluding that many elements of the first plan were implemented, but inevitably, not all were achievable or ultimately deemed necessary/desirable within the timeframe. The second strategic plan set out a number of short-term (1-2 years) and longer-term (3-5 years) priorities.

Short term priorities:

- Develop and implement a Visibility and Dissemination ('PR') policy, i.e. a communication plan. Come up with a regular evaluation cycle of EC activities.
- Formulate a leadership development strategy for EHDN committees that assures continued future membership commitment and diversity ('rejuvenation policy')
- Establish a Science Coordination Committee, a Think Tank, and define its mode of operation. Have it generate novel research ideas, collaborations with SBAC to endorse projects and trials, and evaluate completed projects and trials.
- Continue the Fellowship Exchange Programme; try to expand it by finding external partners, e.g. the Movement Disorder Society (MDS).

Long term priorities

- Re-energize working groups; establish closer ties, collaboration and dialogue.
- Bring EHA membership deeper into EHDN's organization; organize discussions with EHA members on developments and directions.
- Establish ties to other rare diseases networks.
- Position SCC* and CTTF (Clinical Trial Task Force) as entries for companies into the network.
- Get the message out that EHDN is willing to help members obtain international funding.

Many specific aims from the second strategic plan have been realized, some almost entirely and some to a lesser extent, as would be expected, given continued progress of the science, shifting regulatory, ethical and regulatory environments and changing opportunities. Some discussion on the extent to which these priorities were achieved and whether they continue to be relevant is included in the discussion within four principle areas of activity outlined below.

The Strategic Plan for 2023-2028

Many key goals identified in previous strategic plans remain (e.g. identification of novel compounds, better objective outcome measures, how to provide the best care using the existing management options). This third strategic plan builds on, revises and extends the previous two plans to take account of changes in needs and opportunities, in particular changes in the clinical trials landscape, to ensure that EHDN can best use its resources to make most positive difference.

A prime example of a change to the landscape that has impacted on many aspects of this plan is the substantial progress has been made over the last five years in developing potential disease modifying treatments, with a marked increase in the number of interventional trials. The first safety and tolerability trial of a disease modifying treatment (Ionis' Tominersen) was successfully completed, and a follow-on efficacy trial, Generation-HD1, was recruited in record time. This achievement was due in part to the preparatory work that had already gone with respect to site training and preparation, both in Europe and North America, for instance in the context of the Enroll-HD observational study, but also because of EHDN's close collaboration with the trial sponsor, Roche, in site identification and set up. This speed proved unexpectedly critical for obtaining useful results as a recruitment dip over the Covid19 pandemic could have fatally jeopardized the statistical power of the study. There are many consequences of this change in pace. In particular, it heightens the need for: EHDN to focus effort and resources on areas where we are best positioned to makes difference; to be well-informed about new scientific findings and emerging therapies, and to ensure that we keep the EHDN membership well-informed; to position ourselves to be responsive and agile to changing needs as the field progresses.

We have therefore structured the strategy to address these needs as follows:
Relevance. Under "relevance" we propose some new research activities that address specific needs emerging from scientific advances and changes in the clinical landscape. We also acknowledge the importance of continuing to drive research to achieve best standard of care for people currently living with HD.

Communication: A likely inevitable and immediate consequence of the increased clinical trial activity is the emergence of more complex trial results. The treatment arm of the Generation-HD1 trial eventually had to be stopped due to adverse safety signals, and since then another interventional trial taking place in Europe has had to be stopped. The ongoing evaluation of data from these trials is providing important insights into critical aspects of HD, and thus invaluable lessons going forward. EHDN is uniquely positioned in terms of the expertise of its

members and its geographical reach to enable this discussion and promote knowledge exchange. Thus, as set out below, we propose that EHDN develops a new role in mediating the communication of such trial results to the HD community, and we strongly believe that establishing and maintaining these lines of communication should be a high priority. Therefore the communication strategy as outlined below will take this new priority into account.

Network functioning: In order to be in the best position to enable swift and effective communication, to promote collaboration within and outside of the network, and to make best use of the wealth of expertise within EHDN, it is highly important that our knowledge of our own network is accurate and current. This will enable us to be agile in our ability to harness the power of the network and strengthen network resilience.

Sustainability: None of us can afford to ignore the greatest challenge faced by man in the modern era. This is the first time that sustainability has been included in the EHDN strategy and we believe it is important to take the first steps towards ensuring that the network considers, and strives to reduce, its carbon footprint.

Relevance

Supporting Clinical trials

Informative clinical trials remain key to rational therapy development and thus the core mission of EHDN. In addition to the established mechanisms of clinical trial support, such as the trial review and endorsement procedures, EHDN now needs to develop a focus on the regulatory process.

EHDN Regulatory Science Initiative (EHDN-RSI)

There is a need to accelerate clinical translation of new knowledge, which has become increasingly urgent in this era of advanced therapeutics with more invasive interventions and complex trial designs. The challenge is further increased by the desire to design clinical trials targeting populations in HD-ISS stage 1 or even 0 and by the emergence of EU regulations such as GDPR (General Data Protection Regulation) and IVDR (In Vitro Diagnostics Regulation) which are now shaping clinical research practices worldwide, but are also creating asymmetries among regions. Furthermore, the mechanisms to comply with the new regulations can be unclear or are differently interpreted across EU countries, creating challenges for multi-national research projects. Regulatory science in HD has benefitted from the work of the C-Path HD-

RSC, but the key focus of HD-RSC has been to work with North American agencies such as the FDA, rather than with European agencies.

Specific proposal

To create an EHDN forum to discuss regulatory science (improving the development, review, and oversight of new drugs, biologics, and devices that require regulatory approval before dissemination) and conduct projects that advance a regulatory roadmap for the development of HD therapies in Europe. The EHDN-RSI (EHDN-Regulatory Science Initiative) would facilitate a closer dialogue with European Medicines Agency (EMA) and other regulatory agencies in Europe to streamline the adoption of strategies intended to foster drug development and seek clarification for implementing the most critical EU regulations. The creation of EHDN-RSI would align with EMA plans to promote relationships with academic groups as per the EMA strategic plan 2020-2025

Objectives

1. To develop guidance and/or question and answer documents to clarify the implementation of European regulations critical for HD therapy development.
2. To seek regulatory acceptance for emergent Drug Development Tools (DDTs) such as biomarkers, rating scales, statistical modelling, etc. through informal collaboration with regulators at dedicated meeting; innovation task force briefing meetings; scientific advice; and the qualification process.
3. To raise awareness and seek resolution for specific problems related to the design of clinical trials in the early stages of HD-ISS; in particular, to seek recognition that traditional clinical endpoints may not be useful in these stages and that, therefore, novel approaches should be explored and, in appropriate contexts of use, endorsed.

EHDN-RSI will likely comprise a steering committee, a working group and work package teams. Recommendations and other proposals developed by the EHDN-RSI will be submitted to the EHDN executive committee for endorsement on behalf of EHDN.

Stimulating and supporting science

EHDN is particularly well placed to have impact by identifying gaps in knowledge and resources and bringing together the expertise to address these gaps. This is particularly the case where the gaps are ones that require multisite or distributed efforts. EHDN is well-positioned to achieve these aims by bringing together expertise, brokering discussion and debate, providing education and training of the next generation of researchers, and in shaping government and regulatory policy. Currently, EHDN promotes scientific research in various ways; through

promoting critical appraisal of clinical trial protocols and scientific proposals, stimulating new research through working groups and seed funds, promoting collaboration, encouraging new researchers and clinicians to engage in HD research through the Fellowship program, being alert to opportunities and responding to requests and enquiries.

A recent example of an identified knowledge gap is the need to better understand what aspects of animal studies are translatable to humans. The response has been to set up a working group to brainstorm this problem and work out ways to understand the translational pathway better. An example of a resource need is the longstanding recognition of the lack of access to postmortem brain tissue from early and asymptomatic HD gene carriers. The progress in various aspects of fundamental scientific research has made it timely to put effort into setting up a system to collect such tissue and a task force to achieve this has been set up.

The key mechanisms to help the EC and SBAC achieve the above aims are the think tank, the working groups/ task forces, the availability of seed funds and fellowships and other EHDN staff resources. It is therefore essential to ensure that these are working efficiently and are fit for purpose. We the following actions will help to achieve this:

Think Tank

The Think Tank is an EHDN initiative to advance HD research (http://www.ehdn.org/about-ehdn/hd-science-think-tank/) by supporting the EC by giving time and space to discussion of EC proposals, supporting the WGs and TFs, and identifying gaps that are not presently being addressed. The Think Tank systematically interacts directly with the WG lead facilitators and EHDN language coordinators which improves Think Tank understanding of WG goals and needs, provides a point of contact for WG/TF lead facilitators, and aids the promotion of collaboration across WGs to better address important scientific questions, and to attract funding to such collaborative projects.

Moving forward

Expand pool of expertise: Currently, the Think tank has functioned with a small core group, which provides continuity, but it will likely benefit from broadening out engagement, either on an ad hoc or regular basis, in order to bring in fresh ideas and also to build sustainability. Expertise will be adopted from the SBAC, or from other pools of expertise within the EHDN membership. With regard to the latter, a register could be kept of members with specific expertise who are willing to be called on for this and other tasks (such as ad hoc reviewing for SBAC).

Transparency: The think tank has been in place for around 5 years, but has evolved substantially over that time. Although it's existence is now better known within EHDN, there is are limited public understanding of what the think tank does and how to access it. This understanding and transparency are essential for proper working of the think tank and therefore need to be addressed. This will be promoted in several ways: more structured reporting to EC; reporting through Journal of Huntington's Disease and the EHDN website; regular report at the plenary meeting; open web-based sessions for interaction with the membership; regular internal review of think tank activities (two such session have already been conducted).

Working groups (WGs) and task forces (TFs)

The working groups provide a bottom-up approach to address important scientific questions, mainly driven by the expertise and initiative of the lead facilitators and group members and also provide a mechanism to engage expertise within EHDN. Thus WGs cover a wide range of remits, often have a broad focus and may evolve over time. TFs have a narrower, more tightly defined aim and exist to solve a specific question. In the context of the 2017-2022 scientific strategic plan, we continue to promote the visibility of the WGs and TFs and foster collaboration between them. All have been encouraged to produce short mission statements and to outline their aims and strategies. Eighteen groups have now provided these (see http://www.ehdn.org/about-ehdn/ehdn-working-groups/). WG and TFs are peopled by researchers committed to the specific WG/TF subject area and so need to make time for the activities within their own research time. The key resource available for working groups are (i) funding for face-to-face meetings, (ii) access to the EHDN zoom account for meetings, and (iii) access to EHDN seed funds, and (iv) outside grant income. The appraisal of applications for meeting funding is delegated to the Think Tank, and approved by central coordination. Access to seed funds operates as for any other EHDN members

Moving forward

Dissemination and WG interactions: Although there has been some increase in interactions between working groups and dissemination of WG findings, there is still room for improvement.

Two proposed mechanisms are

(i) consider a regular (e.g. annual) virtual meeting of WGs and TFs specifically to allow exchange of knowledge and ideas between WGs and TFs and also to consider hosting ad hoc virtual platform meetings for WG to disseminate and discuss important new findings. We propose asking the WG/TFs for their views and setting up a virtual or in-person meeting depending on the feedback.

(ii) Regular virtual open meetings for WG to disseminate information. These would need to be well curated and well advertised.

(iii) WG outlets through written material such as regular Journal of Huntington's articles and/or EHDN newsletters.

Funding: We can consider how to employ existing staff resources (our existing grants manager) to better support working groups, and whether there are any additional mechansims for WG/TF support. Examples of success in securing external funding are DOMINO, which grew out of the Genetic Modifiers, Environmental, and Physio WGs, and a funding partnership with Roche/SAGE to support quality-of-life research through HEATED. Input from the grants manager was variable in these cases and perhaps a partnership between the grants manager and science director could be considered. Finally, where appropriate, closer collaboration could be encouraged with pre-clinical and clinical units of CHDI to combine expertise and efforts in common projects, funded by CHDI.

Seed fund scheme

EHDN offers a funding scheme (seed funds), ultimately funded by CHDI, with the goal to fund innovative pilot work that may be expected to help lever funding from other sources. Seed funds up to a limit of €50,000 are intended to fast-track pilot studies required to apply for larger grants from other organisations, or to estimate the statistical power needed for larger studies (e.g., in clinical trials). Studies funded through this scheme should result in conclusive answers to the hypotheses under test.

Moving forward

Review of seed funds: The seed funding programme can be considered successful overall. However, the overall proportion of seed fund applications awarded has been relatively low: during each round about 15-20 applications are submitted of which only 1-2 can be funded (success rate 5-13%). Furthermore, there is some evidence that the quality of applications has increased over the years since the scheme started in 2009 whilst the funding cap (50K per application) has not changed. Therefore, it seems timely to reconsider whether the funding formula is optimal. This should start by assessing whether good fundable applications are turned down at each seed fund round. There are several potential mechanisms for collecting such information, one of which would be via the SBAC during the reviewing process. In parallel, stimulating more high quality applications (whether basic science or clinical) could be achieved through networking events / (online) conferences, as well as dedicated education efforts (see under 'Education').

Fellowships

Short term Fellowships are available annually to help young clinicians and scientists develop the expertise they need to best serve the Huntington community. Currently these focus on

acquisition of clinical skills and on applicants from under-served areas. The scheme has been running for several years and it is important that there is now a proper review to (i) revisit the principles of the fellowship scheme to assess whether they are still fit for purpose – for example should we consider whether fellowship could be offered for young HD researchers to visit different labs/learns new techniques, and whether the current policy of regional restriction is appropriate; (ii) undertake a more searching assessment of the success of fellowship program – perhaps by understanding better what EHDN fellows go on to do, and whether they stay in touch with EHDN; and (iii) consider whether there are ways to increase visibility of the program to encourage more/better quality applications.
The review process should include at a minimum the team currently involved in reviewing and managing applications, key EC members.

Other EHDN resources

In the light of the new ambitions, there will be a need for the leadership team to reassess the current deployment of EHDN staff.

Steering Policy

EHDN has been involved in informing policy making; for example, the Heated WG is a WG that was suggested to think tank by an EHDN member – in this case the development of future policy for access to medicines once disease-modifying drugs are developed. However, as already stated in the previous strategic plan, the visibility of HD and EHDN within the European political environment remains relatively low. This includes engagement with policy makers that decide on research and funding priorities within the EU. It is important for EHDN to consciously review the need to be involved in informing and in developing policy making on a European level and on national levels. The need to influence policy may become apparent through WGs such as the EHDN Regulatory Science Group and Advanced Therapies WG where barriers to progress need to be addressed at a political level to lobby for changes in regulation. Currently, there is no systematic mechanism for achieving this and it is not clear what the optimal mechanism would be. Potential mechanisms are discussed in the think tank and brought to the EC to decide on a way forward.

Specific proposals

- Formation of a task force/working group that anticipates the future regulatory challenges and helps meeting these through engagement with partners in industry and in regulatory authorities

- Implementation of more effective communication-strategies: improving the website, increasing social media presence, newsletters and holding public challenges etc. (see Communication).
- Grant Newsletter (tailored to HD): e.g. monthly updates of grant opportunities in a simple 'Grant Newsletter'.
- Increasing advocacy and lobbying at the level of the European Commission: advocacy by patient groups (EHA), joining forces with other advocacy groups for brain diseases as part of OneNeurology https://eurohuntington.org/2021/12/16/a-new-dawn-for-neurological-diseases-on-the-horizon)

Improving care

While we strive for better treatments, it is important to continue to improve care for individuals currently living with the effects of HD. The immediacy of these positive effects are critical for building and maintaining engagement of the HD community, which in turn is a cornerstone for the swift execution of informative trials. It is also an added incentive for today's study participants (in interventional and observational trials) to get involved in projects that will likely only bear benefits for tomorrow's generation the HD community. EHDN is already in a privileged position to promote the dissemination of excellence in care within the European HD community. Through direct experience and through its close relationship with the HD patient organisations, the EHDN membership has a deep knowledge of the needs of HD patients and their families and it also has the broad expertise to address these needs. Also, the infrastructure dissemination such as the Lanco staff and the communications team is available.

We identify 4 key ways in which EHDN can influence care.

Supporting clinical trials of symptomatic treatments; Symptomatic treatment trials can already be submitted for trial endorsement. We don't see a need to radically change this currently, although our openness to supporting symptomatic trials could be better communicated.

Supporting working groups involved in care: A number of our working groups are involved in care issues, some which were suggested by the think tank and duly set up. We proposed that this continues over the next period, but that the discussions involve additional EHDN members who are expert in a range of care issue.

Education and dissemination Specific goals set out in the 2017 plan have largely been achieved - EHDN has successfully partnered with MDS both to fund EHDN fellowships and also to generate a joint virtual training meeting which was well attended. However, a range of new initiatives could be considered. These include:

- More systematic curation and dissemination of resources such as validated guidelines for HD management.
- Team up with partners such as the European Reference Network for Rare Neurological Disorders (ERN-RND) to deliver education on care.
- Online interviews with experts on practical aspects of the disease for people affected by HD.
- Invited (Assigned) talks by experts (basic, clinical and care aspects of HD)
- Training sessions for clinicians
- Online presentations by EHDN care WGs as outlined above.
- Ad hoc meetings to discuss "hot topics" as these arise.

Influencing policy
Involvement in policy for care issues is important to EHDN mission and is discussed above under "steering policy".

The Network

Geographic reach

EHDN is open to membership for all individuals with a genuine interest in EHDN's strategic aims across the whole of Europe. The activities of EHDN, EHDN membership and engagement with EHDN is not homogeneous, with high concentrations of membership in large north-western European countries such as Germany and the UK and lower levels of engagement in some more southerly and eastern countries. This is probably related to the interests of individuals in the more active countries and to demographics, but may also be related to the history of EHDN (i.e. which countries were most engaged in establishing EHDN). The consequence of this is relative under-engagement, with loss of talent in some geographical regions, less support for development of clinical services, reduced opportunity for engaging the whole European workforce for the future. The 2017 plan highlighted the need to rejuvenate EHDN committees by specifically seeking engagement and new membership from young investigators and from areas under-represented. This was achieved by personal contact with potential applicants by the then co-chair and is something that will be continued.

Primary engagement with EHDN is through personal membership. The bar to become an EHDN member is deliberately low as it simply requires a genuine interest in HD, but this has served EHDN well and we see no reason to change it.

There is also engagement through sites, which is also highly important, especially for involvement in clinical trial activities. There has been a relatively informal process for becoming an EHDN site and mapping of sites occurred in the past but has not been revised recently and is now out of date.

The value of addressing these issues includes:

- strengthening engagement of members,
- increasing membership
- bringing in the next generation of members
- more engagement with working groups.
- Better enabling us to engage sites with training and education, and networking.
- Providing recognition for site (potentially certification)

Moving forward

We recognize that currently, the leadership of EHDN has only a partial understanding of the constituency and needs a better understanding the current landscape, which will have the advantage of increasing collective knowledge of our own network and update map of website. Specifically this will entail:

- mapping sites across Europe and getting to know our existing sites better.
- Map clinical sites and preclinical sites (many sites will have both)
- Curation of membership directory

We suggest piloting a program of individual engagement with each site to work out the best way to achieve the mapping process. We may need to develop a better definition of "EHDN sites" and may consider a more structured process for becoming and EHDN site. We see this as an iterative process which will be achieved in conjunction with regular EC discussion.

Potential Mechanisms for supporting non-Enroll sites include:

- Site certification process
- Other resources – CHDI, sponsors, grants

Specific proposals

- Mapping EHDN sites – starting with pilot
- Curation of EHDN membership directory
  Consider site certification process as mechanism to extend support of clinical sites
- Consider mechanisms for best achieving and maintaining engagement from young investigators and under-represented regions.

Communication

EHDN is a network of people. In such a network communication is the means connecting people and thus at the core of how a network works. In its most basic sense, communication is the exchange of information. For EHDN excellent communication both internally and with the outside are critical for efficiently pursuing its mission. Internal communication is fundamental to its success. The communication strategy is under a particular two-tiered developmental stress: the network itself is constantly growing in size and complexity and the communication technologies are evolving particularly dynamically. This constellation gives rise to great opportunities and a few risks, that the communication strategy needs to take into account. A burden is on the staff that needs to adjust to new channels of communication. Decision times for statements get shortened while their reach and impact is expanded. The weight given to efficient communication for the success of EHDN's mission is evident from the status communication has in the different sections of the strategic plan. But additional strategic measures are required to ensure EHDN's vitality and its ability to achieve its mission.

Introduction to the Communication Strategy

The European Huntington Disease Network (EHDN) was launched in 2003 as a natural development and collaboration of European clinicians, researchers, health care professionals and patient advocacy groups. Clinicians, researchers and healthcare professionals face similar challenges depending on the area of expertise, and infrastructure development and collaboration are natural in addressing these challenges. It soon became apparent that a networking and communication strategy needs to be firmly established to allow the long functioning and stabilization of the network and to allow the proper integration of new members in the existing network.

Understanding the Network - The Communications and Networking Tools

To overcome the language barriers and be accessible across Europe, the EHDN has focused from the beginning on developing and implementing an advanced **multilingual platform** to serve as a source of information, communication, and data collection (www.euro-hd.net) and www.ehdn.org .

Maintaining the EHDN Network

- In order to maintain the infrastructure, continuity measures need to be implemented. The curation the existing members and site lists are simple, but effective steps in this direction.
- Personal face to face contact (also online) in the form of short focus interviews will help to improve the contact to existing sites/ centres.

Being New to the EHDN - Process of Integration of the new members into the EHDN

The success of the network depends on the integration of the new members, new sites into the existing infrastructure.

It is important **to provide basic information that outline the purpose, mission, structure, and activities of the EHDN to the new members/ new sites.**

- Introduction to the EHDN and its activities in the form of the personal interview / short conversation – online or in person at the plenary (important would be in a rather short time after becoming the member, maybe in 4-6 weeks)
- Introduction to the other members via existing channels - Social media Platforms (YouTube, Twitter, Facebook, Instagram, …) and LinkedIn.
- Newsletter

What is needed – Tools to be provided to the Network

- Adaptation of the process of the updating the members lists and the site lists and to overview the integration of the new members into the existing network
- Communication Strategy Group to support and lead the process – already existing
- Digitalisation of the process of the different meetings in the network, providing the digital solution to the EHDN members, if possible
- Group of the persons (pool) providing/conducting the welcome and maintaining interviews - the process of action what can be offered in the personal interaction and how we can control if the integration of a new member was successful.

Promoting understanding of clinical trial outcomes

Promoting and supporting informative clinical studies, including regular oversight and monitoring of both observational studies and clinical trials, are core tasks of EHDN. The recent surge in the numbers of trials is associated with high expectations, and, perhaps predictably, entails a number of high-profile failures/set-backs. These inevitable developments bear the very real risk of over-reactions from the trial sponsors and possibly the HD community. By managing expectations, ensuring transparency and facilitating the communication of complex trial results, EHND is developing the important new role of mediator between sponsors and the HD community. Living up to this new challenge will be critical in steering the HD field through setbacks without abandoning or over correcting the course. EHDN recognizes its responsibility to maximise the information that can be learnt from every clinical trial that is initiated and following the termination in dosing of the GEN-HD1 trial, EHDN held a successful virtual meeting to facilitate discussion of the trial between the sponsor, a panel of experts and the community.

Specific proposal

For EHDN to take more of a role in facilitating the interpretation of clinical trial outcomes and in promoting discussion with the relevant scientific and clinical communities. This may be best achieved through a virtual platform and could draw on the expertise of the membership.

The Network and the wider community

The serious impact of impending climate change as one of the greatest threats to mankind is now inescapable. It will impact on our HD families, our membership and our activities. A UK charity commission report found that, more than 10 years ago, most UK charities had already acknowledged the seriousness of the climate emergency and had incorporated specific reporting strategies and actions as part of their ongoing regulation. EHDN will develop and implement a green agenda as part of this strategic plan.

Specific proposals: The think tank should be tasked with generating a route map to improving EHDN climate sustainability, which will then be considered by the EC. This will need to include an estimate of EHDN's total carbon footprint (for example by following established protocols as set out by recognized bodies such as the Carbon Trust https://www.carbontrust.com/). It should also include a range of important considerations, such as balancing the need for in person and virtual meetings, guidance for members' travel and for selection of meeting venues); how to source advice for achieving net zero.