



EUROPEAN **HUNTINGTON'S DISEASE** NETWORK

Summary of EHDN's Scientific Strategic Plan

Established in 2004, the European Huntington's Disease Network (EHDN) is a not-for-profit scientific organisation aiming to advance knowledge of Huntington's disease (HD) by supporting scientific and clinical efforts to develop and test therapeutic interventions that will improve the quality of life of people affected by HD. Since its foundation, EHDN has grown into a well-organised and consolidated European-wide network which is able to design and conduct high-quality preclinical research and clinical studies as well as to offer a network of specialised clinical centres for HD patients. In order to improve the quality and efficiency of research activities within EHDN and to refocus them on EHDN's main mission, a Scientific Strategic Plan was developed in 2011.

The development of the plan took place in three stages:

1. Overview of EHDN research activities from 2004 to December 2010
2. Discussion of the plan with members of the executive committee (EC), scientific and bioethics advisory committee (SBAC) and working group lead facilitators, and draft of the document
3. Review and approval of the plan.

The following objectives were defined to be accomplished by EHDN from 2011 to 2015:

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

Objectives 2, 3, 4 and 9 were selected as short-term objectives to be accomplished until 2013.



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To achieve these objectives, the following strategies were identified:

Strategy	Initiatives	Objectives
1. Improve scientific governance	<ul style="list-style-type: none">☞ create a scientific planning committee☞ create a research manager position☞ nominate a study coordinator for every research project	<ul style="list-style-type: none">⇒ plan scientific activities promoted by EHDN⇒ facilitate the interaction between EHDN's different scientific functional units⇒ identify the scientific needs that may be targeted by the EHDN's initiatives⇒ suggest, promote and implement measures to achieve the established aims keeping in mind the EHDN's mission
2. Implement support facilities to improve scientific output	<ul style="list-style-type: none">☞ create a scientific planning committee☞ create a research manager position☞ optimise the biostatistics support facility☞ create a clinical methodology support facility☞ optimise the medical writing support facility☞ create scientific fellowships	<ul style="list-style-type: none">⇒ maximise the scientific output of EHDN, its research centres or single investigators⇒ draw attention to the quality of EHDN's research⇒ recruit and motivate new active members
3. Improve EHDN's capability to design good-quality clinical trials	<ul style="list-style-type: none">☞ create a clinical trials task-force☞ develop a clinical trials project☞ implement mechanisms to analyse data generated by REGISTRY and other EHDN-related studies☞ support the development, validation and qualification of progression markers	<ul style="list-style-type: none">⇒ improve planning of all activities related to clinical trials (advisory boards, interaction with sponsors/promoters, selection of centres, defining EHDN services to allocate, etc.)⇒ provide consultancy on the design of future clinical trials, developing the clinical study protocol, defining which centres will participate and their geographical distribution



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<p>4. Improve EHDN's capability to conduct clinical trials</p>	<ul style="list-style-type: none"> ☞ create a clinical trials task-force ☞ develop a clinical trials project ☞ create an EHDN clinical trials portfolio ☞ define criteria for EHDN clinical trial sites ☞ define a programme to optimise patient recruitment ☞ define and allocate EHDN clinical trial projects staff ☞ create a clinical trial EHDN services' manual 	<ul style="list-style-type: none"> ⇒ strengthen the capacity to recruit eligible subjects for clinical trials in a reasonable time frame ⇒ improve the overall quality of the data produced
<p>5. Refocus working group objectives</p>	<ul style="list-style-type: none"> ☞ create a scientific planning committee ☞ redefine objectives of working groups in line with the scientific strategic plan 	<ul style="list-style-type: none"> ⇒ refocus the objectives of all active groups in accordance with EHDN's main mission
<p>6. Optimise research funding</p>	<ul style="list-style-type: none"> ☞ create a research manager position ☞ change seed fund regulations ☞ identify new revenue streams to support the EHDN activities and other initiatives that address the EHDN's objectives 	<ul style="list-style-type: none"> ⇒ optimise and guarantee long-term funding of EHDN's activities
<p>7. Stimulate scientific collaboration</p>	<ul style="list-style-type: none"> ☞ create a research manager position ☞ stimulate interactions with other neurodegenerative research networks ☞ invite EHDN's external experts to actively participate in EHDN committees as external advisors ☞ organise a scientific forum that focuses on clinical trial methodology to present the EHDN's capabilities and services to all pharmaceutical companies (potential partners) interested in HD ☞ develop the concept of 'EHDN Ambassador' 	



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<p>8. Improve training (both scientific and clinical)</p>	<ul style="list-style-type: none"> ☞ implement methodological training about aspects relevant to the quality of data collected in clinical studies ☞ develop and deliver innovative educational models that reflect the needs of EHDN projects and HD healthcare professionals ☞ develop EHDN clinical fellowships ☞ develop teaching courses on HD-relevant topics 	
<p>9. Improve communication and EHDN's public recognition</p>	<ul style="list-style-type: none"> ☞ create a scientific planning committee ☞ develop a communication plan focused on recruiting subjects for clinical studies ☞ develop an EHDN introduction video ☞ encourage EHDN members to promote the Network when participating in other meetings ☞ enhance internal communication between working groups, committees and task forces ☞ clarify and communicate the internal organisational structure to members ☞ brand EHDN as an international organisation focused on HD research and healthcare ☞ identify strategies to enhance website visibility ☞ increase EHDN awareness among patient groups and healthcare professionals ☞ improve EHDN's public recognition 	<ul style="list-style-type: none"> ⇒ strengthen communication (between the EHDN groups and with the HD community) ⇒ improve EHDN's public recognition
<p>10. Develop an innovation area</p>		<ul style="list-style-type: none"> ⇒ develop 'translational research' as EHDN's innovation area



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11. Guarantee sustainability	<ul style="list-style-type: none">☞ implement mechanisms to identify calls for HD research☞ develop an EHDN portfolio for call applications☞ identify science management providers☞ find alternative external financing sources☞ apply for all national and international funding sources for research monies that fit the HD concept	⇒ plan the sustainability of EHDN by anticipating any changes in the current model of cooperation and funding
12. Monitor the plan implementation	<ul style="list-style-type: none">☞ periodically monitor the implementation of the plan and all projects that require EHDN funds, any participation of direct or indirect EHDN resources, members on behalf of EHDN or EHDN facilities	
13. Review the plan	<ul style="list-style-type: none">☞ interim audit of the plan after two years and formal audit after five years by external auditors, and preparation of a new plan	

The Scientific Strategic Plan was approved by EHDN's Executive Committee in December 2011 and will come into operation as from 1st quarter 2012.

Summary compiled by Diana Raffelsbauer – Jan 31st, 2012