



For Immediate Release

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Global Huntington's Disease Patient Advocacy Organizations Unite to Form Huntington's Disease Coalition for Patient Engagement (HD-COPE)

Kitchener, Canada // S gne, Norway // New York, USA (September 20, 2017) –

The Huntington Society of Canada (HSC), European Huntington Association (EHA), and the Huntington's Disease Society of America (HDSA) are proud to announce the formation of the Huntington's Disease Coalition for Patient Engagement (HD-COPE), a new global coalition to give families who are affected by Huntington disease (HD) a direct and impactful voice in HD clinical research.

HD-COPE will replace the current *ad hoc* approach to incorporate the patient-voice in therapeutic development efforts in Huntington's disease with a coordinated and consistently knowledgeable mechanism to contribute HD community experience to regulators, industry and researchers. Patient-oriented input is highly needed to meet the needs of the patient community, speed up recruitment and increase retention for all HD clinical trials.



The HD-COPE Advisory Board, comprised of the senior staff of each member organization, will provide counsel to clinical research leaders on broad issues involving patient feedback, community needs and research recruitment. The Advisory Board will also manage a global HD-COPE Team of HD family representatives. Team members will be a select group of volunteers from HD families in each member region who meet the expectations of experience and availability to participate in global clinical research meetings.

"The global Huntington disease community is relatively small compared to other disease communities, which has created the need for us to work collaboratively with no borders. HD-COPE is an example of global HD lay organizations being the conduit of information between pharma and the HD communities to ensure the success of clinical trials. I am optimistic that the facilitation of equal collaboration between the key stakeholders will expedite the path to viable treatments for HD," said Bev Heim-Myers, Chief Executive Officer of the Huntington Society of Canada.

Astri Arnesen, President European Huntington Association added "Our voice matters and by uniting in a global coalition, we will make our voice stronger. I am convinced that contribution from HD-COPE will add value to all aspects of clinical research because we have a unique perspective and knowledge about HD."

"The most effective clinical research meets the therapeutic needs that patients and families have personally identified," said Louise Vetter, President and Chief Executive Officer of the Huntington's Disease Society of America. "HD-COPE will ensure that HD affected families are true partners in clinical research by expanding their role from simply being trial participants to ensuring that the trials have their perspectives, values and thoughts on risks and benefits incorporated from the start. It fundamentally changes HD clinical research from being 'for' or 'about' HD families to being 'with' and 'by' them."

HD-COPE is now organizing two patient advocate teams, one in North America and one in Europe. Collectively, the team will be comprised of approximately 20 members (4 from Canada, 6 from the United States and 10 from Europe). HD-COPE team members will provide their HD patient or caregiver perspective at meetings with regulators, pharmaceutical companies and researchers at meetings organized by the HD-COPE Advisory Board. Each member organization is responsible for recruiting team members from their respective regions.

About the Huntington Society of Canada

The Huntington Society of Canada (HSC) is a respected leader in the worldwide effort to end Huntington disease (HD). HSC is the only national health charity dedicated to providing help and hope for families dealing with HD across Canada. HSC aspires to a world free from Huntington disease. Huntington disease (HD) is an inherited, debilitating brain disorder that is fatal and incurable. About one in every 7,000 Canadians has HD and approximately one in every 5,500 is at-risk of developing the disease. Many more are touched by HD whether as a caregiver, a family member, or a friend. Huntington disease is devastating for both the body and the mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually present between the ages of 30 and 45, and gradually worsen over the 10-25 year course of the disease. Eventually they lead to total incapacitation and death. For more information about Huntington disease and the Huntington Society of Canada visit www.huntingtonsociety.ca.

To learn more about HD-COPE and the role of families from Canada in clinical research, please Contact: Bev Heim-Myers, CEO, Huntington Society of Canada, 1-800-998-7398 info@huntingtonsociety.ca

About the European Huntington Association

The European Huntington Association is a non-profit umbrella organization. We represent 43 member HD associations from 28 countries and more than 30.000 HD affected from all over Europe. Our main objective is to connect the lay and professional HD communities across borders and develop better services and research together. We need to work together because we are better and stronger together! To learn more visit our webpage: www.eurohuntington.org

To learn more about HD-COPE and the role of families from Europe in clinical research, please contact Astri Arnesen at: astri@eurohuntington.org or +4790202031

About the Huntington's Disease Society of America

The Huntington's Disease Society of America is the premier nonprofit organization in the United States dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HD SA is a world leader in providing help for today, hope for tomorrow for people with HD and their families. To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit www.hdsa.org or call (800) 345-HDSA.

To learn more about HD-COPE and the role of families from the United States in clinical research, please contact George Yohrling, PhD at gyohrling@hdsa.org or 212-242-1968, Ext. 211.