
HHT CAB

Karen Topaz Druckman
President HHT Swiss
ePAG VASCERN
HHT CAB member

About HHT Europe

12 HHT Patient Organizations

Italy (2) - France - Spain - Germany - Holland - Norway
- Sweden - Finland - Ireland - Switzerland - Denmark

Potential number of Patients Represented:

100 thousand

90% of which not yet diagnosed



Federation of HHT Patient Organizations



HHT CAB

- ❖ Initial talks in 2018
- ❖ HHT Europe meeting in Oslo November 2018 - Rob Camp invited to present and answer questions.
- ❖ Approved the creation of the CAB at HHT annual meeting in Oslo
- ❖ January 2019 HHT CAB CALL

AMRO HHT 
France
Association Maladie de Rendu-Osler

HHT 
swiss

HHT 
ireland

HHT 
sverige

HHT 
germany

HHT 
norge




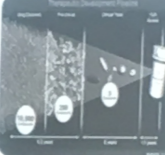

HHT CAB CALL

- ❖ The HHT Europe Board developed the text of the Call; sent to POs
- ❖ The decision was made that each PO would have one delegate of their choosing.
- ❖ It was also decided to include National HHT POs in this process therefore the call was sent to the POs with the request to disseminate and reply with their chosen candidate within a certain deadline.
- ❖ HHT Europe offered advice and assistance for those that had problems finding delegates.
- ❖ In one specific case a PO had no delegate available. HHT Europe advised a public call via social media to find members that weren't in their more active circle of volunteers. The Call was a success and this country found a wonderful and expert candidate.






SCOPE

 <p>Trial protocol All aspects, including informed consent</p>	 <p>Strategy trials Collaboration with competitors</p>	 <p>Compassionate use programme</p>	 <p>Pipeline drug development portfolio and plan</p>	 <p>Reasonable pricing World-wide Access Patent availability to generics companies</p>
--	--	---	--	--

Also Community Relations (DSMBs, Investigator Meetings), marketing practices, and publicity

EURORDIS.ORG



Challenges

- ❖ Different levels of expertise
- ❖ Administration
- ❖ Communicating effectively with national POs





Thank you

