



## **CTO 2018 Clinical Trials Conference**

# **Making it easier for Patients to Understand and Participate in Clinical Trials**

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# Meaningful Engagement is Two Sided

- Clinical Trials do not happen without people – focus on participant needs to ensure recruitment and retention
- Respect the expertise of the family/patient – they are the voice of the lived experience
- Work with pharma/industry to include the patient perspective early in protocol setting process
- Value and educate the patient voice – when creating tools and clinical trial protocols
- Both industry and patients need to be educated about each other's needs

# Preparing for Clinical Trials

- Meetings with Clinicians, partners, industry, staff and HD family members-HD Consortium (5 meetings to date - in process of planning next meeting)
- Created: Clinical Trial Checklist, Preparation Guide, Mentorship program, Clinical Trials Site Map
- Family/patient representation-active participation in all aspects of HD Consortium
- Next Steps:
  - Modules for clinicians to build clinical trial expertise
  - Clinical Trial decision guide for patient-clinician engagement



# HD-Families Advising Clinical Trials

## HD-COPE

- International coalition to add quality to all aspects of clinical trials through patient input
- HSC (Canada), HDSA (US), EHA(Europe) lead coalition - will grow to include family members from other countries
- 4 members from Canada, 6 from US, 10 from Europe
- 2 days training in London, England – demystify the clinical trial process and reinforce their expertise as the family/patients
- HD-COPE team understands the process and vocabulary of clinical drug trials so that their dialogue with industry is effective and efficient

# Advisory Board with HD-COPE and Industry

- First time Roche engaged patient input this early in protocol setting
- Roche came to the table to learn about the burden of HD and considerations that need to be made
- Family/patients felt empowered and respected
- Game changer for pharma and families

# HD Buzz

## Understanding the Research

- Web portal to access, peer-reviewed, evidence-based HD research and clinical trial information in everyday language
- Critical and accessible research and clinical trial information for families
- Interactive site for families, health care providers, researchers
- HSC worked with creators before launch in 2010 and 1<sup>st</sup> to commit to annual funding
- 200,000 views per month
- Information provided in 15 languages

# Genetic Non-Discrimination Act

- Legislation passed and received Royal Assent – May 4, 2017
- Genetic Discrimination is a barrier to clinical trial participation
- Quebec Government referred legislation to Quebec Appeals Court
- Canadian Coalition for Genetic Fairness (CCGF) granted intervenor status
- Currently our genetic test information is protected by law. CCGF will continue to fight to ensure the law is not overturned

"Coming together is a beginning, staying together is progress, and working together is success." – Henry Ford

Thank You!