



Presentation to CTO 2017
Clinical Trials Conference

A Winning Strategy to Meaningful Community
Engagement in Clinical Trial Readiness

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Meaningful Engagement

- Include Community on a variety of levels
- Authenticity
 - Build trust
 - Ask for input and use it
 - Value the community voice – learn from it
- Two way street – clearly articulate what’s in it for them
- Clinical Trials – they won’t come just because you build it – they will come if they trust what you have built

Clinical Trials Readiness

Be Brave, Be Bold, Be Ready

- 2012 created a roundtable of researchers, clinicians and family members to advance HD Clinical Trials in Canada. 5 meetings to date resulting in a formal organization called the HD Consortium
- Created: Clinical Trial Checklist, HD Clinical Trials Preparation Guide, Mentorship program, HD Clinical Trial locations map – Family members have added value to all from initial discussion to creations
- Family representation-active participation in Executive consortium calls

HD-Families Advising Clinical Trials

HD-FACT

- Global advisory panel of lay organizations to inform pharma re: clinical trial prep of participant materials
- HSC (Canada), HDSA (US), HAD (UK), EHA(Europe)
- Pharma creates draft communication tools, surveys for review by lay communities
- All organizations engage family members to provide feedback and it is shared with Pharma
- Pharma is incorporating feedback

Million Dollar Research Match

- Donor (family member) generously donated dollars
- Donor involved in Round Table discussion with thought leaders in HD research when creating research initiative
- Round Table resulted in proposal for match dollars
- Research initiative launched – donor is kept informed

HD Buzz.net

- Web portal to access HD research and clinical trial information in everyday language
- Interactive site for families, health care providers, researchers
- HSC worked with creators before launch in 2011 and fund site annually
- In February – 197,557 home views
- Information provided in 15 languages
- Upcoming study – Does HD Buzz increase appetite for research and trial participation

Canadian Coalition for Genetic Fairness

- Established in 2008 – 20 member organization
- First concern expressed by HD Researcher and community members – no participation in clinical trials until genetic information protected
- HSC does heavy lifting at federal and provincial levels to pass legislation
- This Advocacy effort is Community driven
- Bill S201 – Genetic Non-Discrimination Act

“When you’re surrounded by people who share a passionate commitment around a common purpose, anything is possible.”

Howard Schultz (CEO Starbucks)

Thank You!