

## Seeking Feedback

The Communications Department at the Huntington Society of Canada is seeking feedback regarding Strength and Knowledge (S&K). Since 2008, S&K has been an e-bulletin focused on HD service and care.

Please take a moment to participate in the survey below so we can provide you with information that interests you.

Let us know what you think by February 21, 2013.



The Huntington Society of Canada has many educational materials available to help individuals and families living with HD to cope with all aspects of the disease. Publications, publication excerpts, fact sheets are all available on the HSC website in the following categories: Individuals with HD; Those At-Risk; Caregivers; Families; Professionals.

# Strength & Knowledge

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## Shape the Future

**With potential treatments for HD in the pipeline, now is the time to sign up for clinical trials**

**By Julie Stauffer**

There may not be meaningful treatments for HD today, but all that could change very soon. Today, many promising treatments are getting close to the point of human testing. And that's where you come in.

"We don't know whether it's going to be tomorrow, next week, next month, one year or five years from now, but we know that we need to reach out to the HD community in order to ensure that everybody that's interested and willing to be involved in clinical trials have raised their hand," says Maribeth Meijer, HSC's Director of Family Services and Community Development.

Clinical trials can't run unless people sign up to participate. As Dr. Jane Paulsen indicated at our National Conference last November, one of the biggest barriers to research right now is the shortage of volunteers for trials.

Everyone has a role to play, whether you have the HD gene mutation of not, are at-risk, or are symptomatic. By compiling a list of potential volunteers now, we want to be ready for the moment when clinical trials open up.

Looking for a few good reasons to get involved?

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## EHDN's Standards of Care for HD patients

*"The most comprehensive effort so far to document best practice in the clinical management of HD".*



EUROPEAN HUNTINGTON'S DISEASE NETWORK

**Make sure trials run.** Because HD is a relatively rare disease, researchers often struggle finding enough participants to create scientifically relevant results. Without enough volunteers, trials simply can't go ahead. "We really need to tap the whole community," Maribeth explains.

**Accelerate progress.** Once potential treatments are ready for testing, signing up right away helps researchers get results as quickly as possible. If a drug works, speedy trials reduce delays in getting it to market. If it turns out a drug doesn't work, the sooner researchers find out, the sooner they can shift their focus to other promising avenues.

**Get access to treatments that could change your life.** There's no guarantee the drug you're testing will prove effective. If it does, however, you'll be getting the benefits long before it's available to everyone. "If you aren't ready and you aren't on one of the lists, then you may miss the opportunity to participate," says Maribeth.

Help us speed up the path to meaningful treatments. Contact your closest Huntington Society Family Services team member to learn more about getting involved in clinical trials.

You don't need to make any commitment up front. We'll give you more information and help you consider the choices. Then, when clinical trials open up near you, you will be on the list of potential participants.

We can also help you think through the question of getting tested, since some studies may need volunteers who know their genetic status. These are significant life decisions, and we're here to offer support.

Contribute to the solution, for this generation and for generations to come. Count yourself in!

*Right now, PREDICT-HD needs more gene-positive volunteers. The goal of this study is to pinpoint the earliest symptoms of HD. Once clinical trials start, this information will be vital to judge the success of potential treatments. For details, contact your closest HSC Resource Centre director or family services worker. Click [here](#) for a contact list.*



HSC is a proud supporter of HDYO an International organization to help young people who are affected by HD. Visit [www.HDYO.org](http://www.HDYO.org)

## Staying Connected

Please visit our website and fill out our confidential contact information form to receive email communications from HSC. According to your preferences, we'll communicate with you in confidence by email about research findings, clinical trials, best practices of care, local and national events and happenings, volunteer opportunities, etc.

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