

# CONTEMPLATING PARTICIPATING IN A CLINICAL TRIAL?

People, who have participated in research in the past, say that only you can decide if this is the right decision for you, but the information that you may be adding to the knowledge of HD can be invaluable.

The Huntington Society of Canada (HSC) recognizes that some individuals at-risk for HD may choose not to participate in clinical trials, as genetic information is not protected in Canada. Genetic test results can be used to the detriment of an individual by insurance companies and employers in Canada. The Society is advocating for genetic fairness in Canada, however, at this time, protection is not in place. Choosing to participate in clinical trials is a personal decision; the Society encourages those who are interested to consult with their neurologist, HD clinic team, HD Resource Centre Director or Family Service Worker to understand all aspects of this decision.

The following are some potential questions to frame your discussion with a clinician and determine expectations before, during and after a clinical trial. This is not a complete list, it is meant to give you some ideas on what you might like to ask when consulting a clinician. We suggest you choose the questions that are most important to you and think of more questions you may wish to ask.

## ABOUT THIS TRIAL

- What exactly is a clinical trial?
- What clinical trials are available for me to participate in?
- Why do you think participating is a good idea for me?
- How long will the appointments be?
- Is there someone I can talk to who has been in the trial?
- How often will I have appointments?
- Do I have to go through predictive testing to participate?

## DETAILS OF THE TRIAL

- What do the researchers hope to achieve from this trial?
- Why do the researchers believe that the treatment being studied may be better than the one being used now? Why may it not be better?
- Can you provide information about this trial that I can review with my family doctor?

## TECHNICAL QUESTIONS

- What does informed consent mean?
- What kinds of tests and treatments are involved?
- If I experience improvement during the treatment will I have access to the drug after the trial?
- Will I be told about the trial's results?
- Will it be possible to continue receiving the treatment "off label" if it is shown to be effective?
- How long do I have to make up my mind about joining this trial?
- Who will know if I am on a placebo or the actual treatment?
- What are the exclusions that would prevent me from participating in this trial?
- Can I or should I bring a support person/ family member to my clinical trial appointments?
- How long, if I choose to participant, will I be involved in this clinical trial?

## POINT OF CONTACT QUESTIONS

- Who can I speak with about questions I have during and after the trial?
- Who will be in charge of my care?

# Clinical Trials: Questions to Consider

## RISKS AND BENEFITS

- What are the possible side effects or risks of the new treatment?
- What are the possible benefits?
- How do the possible risks and benefits of this trial compare to those of the standard treatment?
- What are my rights as a participant?
- How will my health information be kept private?
- What happens if I decide to leave the trial?

## COSTS

- Where is the clinical trial located?
- Will I have to pay for any of the treatments or tests?
- Will my travel expenses be covered?
- What is the process for reimbursement?
- Who pays if I'm injured in the trial?
- Who can help answer any questions from my insurance company?

## HOW WILL THIS AFFECT ME?

- Will information be shared with my family doctor or specialist?
- How could the trial affect my daily life?
- How often will I have to come to the hospital or clinic?
- Will I have to stay in the hospital during the clinical trial? If so, how often and for how long?
- Will I have check-ups after the trial?
- How would participating in this clinical trial affect my ability to participate in other trials at the same time or at a later date?
- Are there any dietary restrictions or instructions for this trial?
- Will the treatment prevent me from working or participating in regular activities?
- What if I have side effects? Who do I call? Which ones are serious and need immediate attention?

## TREATMENT CHOICES

- What are my other treatment choices, including standard treatments?
- How does the treatment I would receive in this trial compare with the other treatment choices?
- What will happen without treatment?

## FINDING CLINICAL TRIAL LOCATIONS IN CANADA



[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

