

IF YOU OR SOMEONE YOU CARE FOR IS LIVING WITH CEREBRAL PALSY AND INVOLUNTARY **MOVEMENTS THAT ARE DIFFICULT** TO CONTROL (DYSKINESIA), CONSIDER THE KINECT-DCP STUDY.



WHAT YOU SHOULD KNOW ABOUT **CLINICAL RESEARCH STUDIES**

Clinical research studies aim to answer specific questions about how medicines work in the volunteers who take them. You should feel fully informed about what to expect from participation in a clinical research study.

Researchers use clinical research studies to:

- Answer specific health questions
- Learn about the effects and safety of study drugs
- Help find new ways of using approved medications

Regulations and policies have been developed to help protect the rights, safety, and well-being of people who take part in clinical research studies and to help ensure that these studies are conducted according to strict scientific and ethical principles. Before a clinical research study can begin, an independent institutional review board (IRB), research ethics board (REB), or ethics committee (EC) must review and approve the research study.

Participation in any clinical research study is completely voluntary, and you may withdraw from the study at any time for any reason. Before volunteering for a clinical research study, it is important to weigh the potential risks and benefits of participation, which the study team will inform you of, as well as possible side effects. To make an informed decision, gather as much information as possible and talk to your healthcare providers about any questions you may have.

If you have any questions, please contact the study team listed here:

Site name: <u>Kennedy Krieger Institute - Clinical Trials Unit</u>

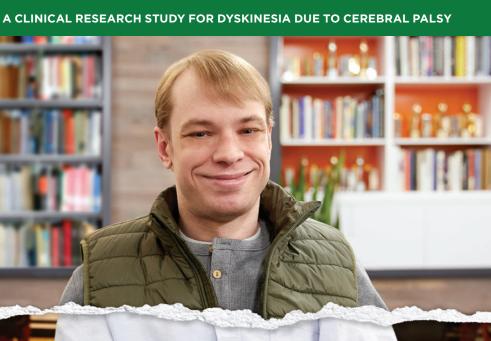
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WHAT OPPORTUNITIES **COULD BE CREATED THROUGH CEREBRAL PALSY RESEARCH?**



Principal Investigator: Dr. Heather Riordan



ABOUT CEREBRAL PALSY

As you may know, CP is a group of disorders that affect a person's ability to move and maintain balance and posture. "Cerebral" refers to the brain, while "palsy" means the condition has to do with weakness or difficulty with movement. One type of CP is dyskinetic cerebral palsy (DCP), which means a person has CP and experiences involuntary movements that are difficult to control.

These movements may be:

- Twisting and repetitive movements or postures known as dystonia
- Slow writhing movements known as athetosis
- Abrupt, jerky, or irregular movements known as chorea

Involuntary movements due to CP occur when part of the brain known as the basal ganglia are not working normally. The basal ganglia are responsible for coordinating movement messages in the brain, which means they regulate voluntary movements. Damage to this area of the brain can result in "too much" movement and uncontrollable or unintended postures.





The purpose of the Kinect-DCP Study is to find out if the study drug, called valbenazine, is safe to use and if it helps to treat involuntary movements that are difficult to control (dyskinesia) due to CP.

The study drug, valbenazine, is a once-daily oral medication. Researchers are comparing the effects of the study drug to placebo (without active medication) in the first treatment period, which lasts 14 weeks. The placebo looks just like the study drug but does not contain active ingredients. Placebos allow researchers to fully understand the effects of the study drug. In the second treatment period, which lasts 32 weeks, all participants will receive the study drug.



Eligible participants must:

- other than CP

There are additional eligibility criteria, which the study team will discuss with you.

EXPLORING MORE POSSIBILITIES FOR CEREBRAL PALSY

Right now, research is underway on a study drug for involuntary movements that are difficult to control due to CP, and if you or the person you care for has CP, this study may be of interest to you. This clinical research study is an opportunity to participate in the development of potential treatments for people living with CP.

ABOUT THE KINECT-DCP STUDY

WHO CAN PARTICIPATE?

- Be a child, adolescent, or adult 6 to 70 years of age
- Have a confirmed diagnosis of dyskinesia
 - (involuntary movements) due to CP
- Not have involuntary movements due to conditions

For more information, visit KinectDCPstudy.com.

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