

What is the purpose of this research tissue bank?

We collect, process, and store samples and information from people with dystonia and related conditions until researchers anywhere in the world need them to do research.

Samples and information in this bank will be used for research on dystonia and related movement disorders. However, tissue samples in this bank can be used for research on any condition.

Who can take part?

Anyone age 7 or older:

- diagnosed with any type of dystonia or parkinsonism
- known to have a dystonia-causing gene change (i.e. positive genetic testing)
- at-risk (25% or greater) to have a dystonia-causing gene change

AND

Family members age 18 or older of people diagnosed with dystonia or parkinsonism.

What would I have to do?

- Give your medical and family history information
- Give a blood sample
- Give your contact information

- Have a videotaped physical exam

Many people will qualify for additional **optional** procedures such as giving a skin sample. When giving a skin sample, a doctor or nurse numbs the skin and removes a piece of skin about the size of the hole at the tip of a pen. People who choose to give a skin sample will bleed and get a small scar.

You can choose one in-person research visit or take part “long distance” over the phone, mail and email.

How long would I take part?

It will take you about 45 – 75 minutes to finish one research visit. Many people will have additional videotaped exams over several years.

What else do I need to know?

We get DNA and cells from the blood sample for genetic research. This tissue is kept forever. Research genetic test results are **NOT** available to people join the research bank. You will get no direct benefit from taking part in this research.

Taking part in research is voluntary.

If you would like to learn more or take part in this research study, please complete the attached form.

Please complete the contact information, read the statement and sign at the bottom. Please return the form to the research coordinator at the address or email below

Name: _____

Mailing address:

Phone (day): _____

Phone (evening): _____

Email address: _____

How would you like to be contacted? (Please check one)

- Mailing address
- Phone
- Email address

I understand that a research coordinator may contact me to obtain additional information, consent or referral to other family members.

Signature: _____

Date: _____

Research Coordinators:
Trisha Mulhaupt-Buell
Melanie Supnet and Caroline Nelson
Massachusetts General Hospital
The Collaborative Center for XDP
114 16th Street, Room 3011
Charlestown, MA 02129
F: 617-724-1823
DystoniaResearch@partners.org



MASSACHUSETTS
GENERAL HOSPITAL

NEUROLOGY

To take part in the DYSTONIA
PARTNERS RESEARCH BANK

Please complete the enclosed form and
return it to a research coordinator

OR

Contact a research coordinator,
Trisha Multhaupt-Buell at
(617) 726-5470
tmulthaupt@partners.org

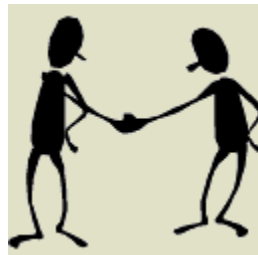
or

Melanie Supnet at
(617) 724-3856
msupnet@mgc.harvard.edu

or

Caroline Nelson at
(617) 726-1208
cnelson@mgc.harvard.edu

Thank you for your time and
consideration of our research bank



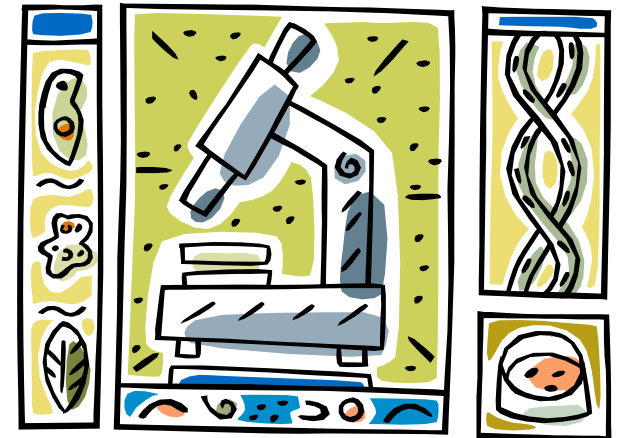
DYSTONIA PARTNERS RESEARCH BANK

And

The Collaborative Center for
X-linked Dystonia
Parkinsonism

at

Massachusetts General Hospital



What is dystonia?

Dystonia (“dis toh nee uh”) is a
neurological movement disorder.

People with dystonia have involuntary,
sustained muscle contractions. These
involuntary muscle contractions can
cause twisting, repetitive movements
and abnormal postures. This happens
because the brain sends signals telling
muscles to tighten and contract
inappropriately.

Dystonia can affect any part of the body
including limbs, hands, torso, face, neck
or vocal cords.

What is DYT3 dystonia or XDP?

People with Filipino ancestry can have
an inherited dystonia, called DYT3
dystonia or XDP (X-linked Dystonia
Parkinsonism). In these families, male
relatives experience dystonia,
parkinsonism or both. Parkinsonism is a
term that describes symptoms of tremor,
slowness of movement, or poor balance.

Principal Investigator: Nutan Sharma, MD, PhD

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