

The NBIA Disorders Association Research Registry

Contact information for ongoing clinical research studies
of Neurodegeneration with Brain Iron Accumulation (NBIA)

Please print

Individual(s) with NBIA: (1) _____ DOB: _____

(2) _____ DOB: _____

(3) _____ DOB: _____

If there are additional family members, please include their names and ages on the back of this page.

Parent/Guardian's name (if applicable): _____

Contact Address: _____

City: _____ State: _____ Zip: _____ Country _____

Phone (day): _____ Phone (eve): _____

E-mail: _____

I prefer to be contacted by: e-mail phone regular mail

Please circle either Y or N: Are you willing to have registry information shared with other research groups studying NBIA? (We will ensure the highest level of confidentiality and notify patients if their information is released to another research group) Y / N

If you have any questions, please feel free to contact us:

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President, NBIA Disorders Association
2082 Monaco Ct.
El Cajon, CA 92019-4235
(Ph) 619 588-2315
(Fax) 619 588-4093*

For each of the individuals with NBIA, please complete the following:

(1) First Name: _____

Primary Care Physician (PCP): _____

PCP's Address: _____

PCP's Phone #: _____

Neurologist: _____

Neurologist's Address: _____

Neurologist's Phone #: _____

Currently taking pantothenate (pantothenic acid, calcium pantothenate)? Y / N

If yes, what is the daily dosage? _____ When was pantothenate started? (mo/yr) _____

Currently taking a supplemental multivitamin? Y / N

Has the *PANK2* gene been tested in this individual? Y / N

Do you have a copy of the results in your possession? Y / N

(2) First Name: _____

Currently taking pantothenate? Y / N

If yes, what is the daily dosage? _____ When was pantothenate started? (mo/yr) _____

Currently taking a supplemental multivitamin? Y / N

Has the *PANK2* gene been tested in this individual? Y / N

(3) First Name: _____

Currently taking pantothenate?: Y / N

If yes, what is the daily dosage? _____ When was pantothenate started? (mo/yr) _____

Currently taking a supplemental multivitamin? Y / N

Has the *PANK2* gene been tested in this individual? Y / N

*If individuals 2 and 3 have a **different** primary care physician or neurologist, please complete page 3.*

(2) First Name: _____
Primary Care Physician (PCP): _____
PCP's Address: _____

PCP's Phone #: _____
Neurologist: _____
Neurologist's Address: _____

Neurologist's Phone #: _____

(3) First Name: _____
Primary Care Physician (PCP): _____
PCP's Address: _____

PCP's Phone #: _____
Neurologist: _____
Neurologist's Address: _____

Neurologist's Phone #: _____