



FND Scientific Registry Surveys

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Initial Survey

Introduction

▼ Introduction

▼ Survey Introduction

Thank you for registering with the FND Scientific Registry!

The purpose of the Scientific Registry is to create a platform for patients with FND to engage and contribute to medical research about the condition and its clinic care, causes, diagnosis, and treatment. By engaging patients, disease advocacy organizations, providers and researchers with this platform, it is expected that clinical research will be accelerated, increasing the understanding of the condition and supporting the development of more effective treatments.

With this study, patients enrolling in the scientific registry will self-report (or report on behalf of a dependent) answers to survey questions online at a time and place that is convenient for them. It is expected the survey may take less than 1 hour to complete. The survey aims to collect baseline information about patient's diagnosis, age at onset, symptoms, physical functioning, treatment protocols, and impact on life. It is recommended you may want to take this survey at a time you have sufficient energy and when you won't be interrupted.

If a question is long, you may have to scroll up to the top of the page to see the next question, rather than down.

There will be additional surveys you may choose to participate in at your convenience after you have completed this initial survey.

Thank you for joining the registry! Patient participation is vital to research and your willingness to participate will help contribute to a greater understanding of the treatment and, we hope, more effective treatments.

Demographics

▼ Demographics

▼ Marital Status

▼ My current marital status is...

☐ Never married

☐ Married

☐ Living as married

☐ Widowed

☐ Separated

☐ Divorced

☐ Remarried

Source: Genetic Alliance PEER

Gender

My gender (self-identified) is...

☐ Female
☐ Male
☐ Other (specify on next question)

I describe my gender as "Other" because I am...
My gender is...

Source: Genetic Alliance PEER

Race & Ethnicity

My race or origin is...

Please select all that apply.

☐ American Indian or Alaskan Native (i.e. Navajo, Mayan, Tlingit, etc.)
☐ Asian (i.e. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)
☐ Black or African American (i.e. African American, Haitian, Nigerian, etc.)
☐ Hispanic, Latino, or Spanish origin (i.e. Mexican, Mexican American, Puerto Rican, Cuban, Argentinian, Colombian, Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)
☐ Native Hawaiian or Other Pacific Islander (i.e. Native Hawaiian, Guamanian or Chamorro, Samoan, Fijian, Tongan, etc.)
☐ White (i.e., European, Middle Eastern, Northern Africa, etc.)
☐ Some other race or origin

The name of my tribe is...
More specifically my Asian heritage is...
More specifically my Hispanic or Latino heritage is...
More specifically my Pacific Islander heritage is...
More specifically my "Other" background is...

Source: Genetic Alliance PEER

▼ Work Status

▼ Are you currently working?

☐ Yes - Full Time

☐ Yes - Part Time

☐ No - unable to work

☐ No - not working (retired, etc.)

☐ Looking for work

☐ Out of work

Source: FND Hope

▼ Has FND changed your ability to work?

☐ Yes - had to quit working

☐ Yes - have had accommodations made to be able to continue to work

☐ No - am able to work as before FND

☐ No, was not working at onset of FND

Source: FND Hope

▼ What accommodations were made to enable you to continue to work?

☐ Reduction of hours

☐ Change of job function

☐ Modification of physical environment

☐ Other

▼ What other accommodations were made to allow you to continue working?

Source: FND Hope

▼ Did the accommodations enable you to resume work, either on a full or part time basis?

☐ Yes

☐ No

Source: FND Hope

Are you currently volunteering?

☐ Yes - Full Time
☐ Yes - Part Time
☐ No - unable to volunteer
☐ No - uninterested

Source: FND Hope

Disability Insurance

Are you receiving disability benefits?

☐ Yes
☐ No - not applied
☐ No - applied and not been approved
☐ No - denied

Source: FND Hope

Diagnosis

Diagnosis

Diagnosed Neurological Condition

Many term(s) are used to describe functional neurological disorders. Which term(s) have your doctor(s) diagnosed you with?

☐ Functional Neurological Disorder (FND)
☐ Functional Neurological Symptoms Disorder
☐ Functional Movement Disorder (FMD)
☐ Conversion Disorder (CD)
☐ Psychogenic Movement Disorder
☐ Somatoform/Somatization Disorder
☐ Non-Epileptic Seizures/Psychogenic Non-Epileptic Seizures (PNES)/Non-Epileptic Attack Disorder (NEAD)/Dissociative Seizures
☐ Dissociative Disorders
☐ Functional Weakness Disorder
☐ Functional Dystonia
☐ Medically Unexplained Symptoms (MUS)
☐ Other

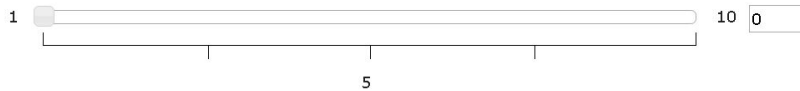
Though there are many names used in diagnosing this condition, for simplicity's sake, we will refer solely to FND throughout the rest of the survey. Use of FND in this sense is meant to encompass all of the names of the condition listed here. We use this umbrella of FND in the following way: "the term *functional* is **not** used as a synonym for *psychogenic*, but instead as a way of describing a group of disorders in which there is a functional rather than structural disturbance in nervous system function..." (Stone & Carson, *Functional Neurological Disorders*. June 2015).

▼ The Other Diagnosed Condition is:



Source: FND Hope

▼ Based on the definition of FND provided in the previous question, how confident are you that FND is the correct diagnosis for your symptoms?



Source: FND Hope

▼ Diagnosing Physician



▼ I was diagnosed by a: (If you had more than one diagnosing doctor, please list the physician who gave your most recent diagnosis.)



- ☐ Primary Care Physician/General Practitioner
- ☐ Neurologist - General Neurologist
- ☐ Neurologist - Movement disorders specialist
- ☐ Neurologist - Neuromuscular specialist
- ☐ Neurologist - Epilepsy specialist
- ☐ Neurologist - Stroke specialist
- ☐ Neurologist - Other
- ☐ Psychiatrist/Neuropsychiatrist
- ☐ Psychologist
- ☐ Other

Source: FND Hope

▼ Doctor First and Last Name



Please list your doctor's first and last name. We ask this information because it is helpful for researchers recruiting patients to be able to verify the diagnosis. It allows us to identify other doctors treating patients with FND.

If you had more than one diagnosing doctor, please list the physician who gave your most recent diagnosis. If you do not know the name of the doctor that diagnosed you, please enter *Unknown*.

▼ Doctor Location - City

If you had more than one diagnosing doctor, please list the city where the physician who gave your most recent diagnosis was located.

▼ Doctor Location - State/Province

If you had more than one diagnosing doctor, please list the state/province where the physician who gave your most recent diagnosis was located.

▼ Doctor Location - Country

If you had more than one diagnosing doctor, please list the country where the physician who gave your most recent diagnosis was located.

As you begin typing, the name of the country will appear for you to select.

Source: FND Hope

▼ I receive treatment (not just the diagnosis) from the same physician.

☐ Yes

☐ No

Source: FND Hope

▼ Age

▼ Please check your age at the points below:

	10 and under	11-19	20-29	30-39	40-49	50-59	60-69	70+
Age at first doctor's visit for FND symptom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Age at first FND symptom	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Age at Diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: FND Hope

▼ Time to Diagnosis

▼ How long did it take to get your diagnosis from the time you first saw a doctor for FND symptoms?

☐ 1 month or less

☐ More than 1 month but less than or equal to 3 months

☐ More than 3 months but less than or equal to 6 months

☐ More than 6 months but less than or equal to 1 year

☐ More than 1 year but less than or equal to 3 years

☐ More than 3 years but less than or equal to 5 years

☐ More than 5 years

Source: FND Hope

▼ Number of Doctors

▼ How many doctors did you see before you got your diagnosis? (Slide the scale or enter a number in the box)

1

10

0

1

5

10

Source: FND Hope

Impact on Life

▼ Physical Functioning (RAND SF-36)

The following items are about activities you might do during a typical day. **Does your health now limit you** in these activities? If so, how much?

Please answer these according to how you feel during a typical day.

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking more than a mile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several blocks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: Rand 36-Item Short Form Survey (SF-36)¹

▼ Mental Wellbeing

▼ If you are suffering from depression or anxiety, when did onset of these symptoms occur?

- ☐ Before FND
- ☐ At the same time as FND onset
- ☐ As a result of illness/disability with FND
- ☐ No depression or anxiety

Source: FND Hope

¹ As part of the Medical Outcomes Study (MOS), a multi-year, multi-site study to explain variations in patient outcomes, RAND developed the 36-Item Short Form Health Survey (SF-36). SF-36 is a set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon patient self-reporting and are now widely utilized by managed care organizations and by Medicare for routine monitoring and assessment of care outcomes in adult patients.

▼ Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble falling or staying asleep or sleeping too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling tired or having little energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor appetite or overeating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling bad about yourself -- or that you are a failure or have let yourself or your family down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble concentrating on things, such as reading the newspaper or watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoughts that you would be better off dead or of hurting yourself in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

▼ If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

☐ Not difficult at all
☐ Somewhat difficult
☐ Very difficult
☐ Extremely difficult

Source: Patient Health Questionnaire - 9 (PHQ-9).

▼ Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all (0)	Several days (1)	Over half the days (2)	Nearly every day (3)
Feeling nervous, anxious, or on edge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to stop or control worrying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying too much about different things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble relaxing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being so restless that it's hard to sit still	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming easily annoyed or irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling afraid as if something awful might happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

▼ How difficult have these made it for you to do your work, take care of things at home, or get along with other people?

☐ Not difficult at all
☐ Somewhat difficult
☐ Very difficult
☐ Extremely difficult

Source: Generalized Anxiety Disorder -7 (GAD-7) Scale²

▼ Quality of Life

▼ Please indicate how your quality of life has been affected since onset of FND.

	Better	No Change	Worse	Not applicable
Quality of Life - Overall	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daily Living/Basic Chores	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marriage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships with other family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships with friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to drive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: FND Hope

Symptoms

▼ Symptoms

▶ Start of Symptoms

▶ Onset

▶ Triggers

▶ Warnings

▶ Duration

▶ Symptoms of FND

▶ Course of Illness

² The GAD-7 originates from Spitzer RL, Kroenke K, Williams JB, et al; A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006 May 22;166(10):1092-7. GAD-7 © Pfizer Inc. all rights reserved; used with permission.

▼ Start of Symptoms

▼ In the year prior to onset of your FND symptoms, have you experienced any of the following

☐ Infection (i.e cold, flu, ear, etc)/Post-Viral

☐ Surgery (Post-Operative)

☐ Head Injury (i.e. Concussion)

☐ Vaccination

☐ Non-head Injury (i.e. back injury)

☐ Accident (i.e. car accident or other)

☐ Emotional stress

☐ Nothing/Unknown

☐ Other

▼ Other related occurrences:

Source: FND Hope

▼ Onset

▼ Over what period of time did the condition develop?

☐ Hours

☐ Days

☐ Weeks

☐ Months

☐ Years

Source: FND Hope

▼ Triggers

▼ Which of the following trigger your symptoms?

☐ Stress

☐ Anxiety

☐ Exhaustion

☐ Physical Exertion

☐ Pain

☐ Startle

☐ Light- flickering or brightness

☐ Touch

☐ Noise

☐ Chemical exposure

☐ Lying down

☐ Standing up

☐ Menstrual cycle

☐ Change of temperature

☐ Change of routine

☐ Happens during sleep - I'm aware

☐ Happens during sleep - I'm unaware

☐ Unaware of triggers

☐ Other

▼ Other triggers I have include

Source: FND Hope

▼ Warnings

▼ Do you get a warning in advance of symptom onset?

☐ No

☐ Sometimes

☐ Always

☐ Know usual triggers and most episodes are triggered by those

Source: FND Hope

▼ Duration

▼ How long have you been living with FND since your diagnosis?

☐ 6 months or less
☐ More than 6 months but less than or equal to 1 year
☐ More than 1 year but less than or equal to 3 years
☐ More than 3 years but less than or equal to 5 years
☐ More than 5 years

Source: FND Hope

▼ Symptoms of FND

▼ During the past month have you been bothered *a lot* by...?

When you have finished this question, please manually scroll back to the top of the survey to see the next question.

	Yes	No
menstrual pain or problems	<input type="radio"/>	<input type="radio"/>
feeling tired or having low energy	<input type="radio"/>	<input type="radio"/>
paralysis or weakness of an arm or leg	<input type="radio"/>	<input type="radio"/>
pain or problems during sexual intercourse	<input type="radio"/>	<input type="radio"/>
trouble sleeping	<input type="radio"/>	<input type="radio"/>
double or blurred vision	<input type="radio"/>	<input type="radio"/>
little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>
difficulty swallowing or a lump in the throat	<input type="radio"/>	<input type="radio"/>
feeling down, depressed or hopeless	<input type="radio"/>	<input type="radio"/>
headaches	<input type="radio"/>	<input type="radio"/>
difficulty speaking or slurred speech	<input type="radio"/>	<input type="radio"/>
chest pain	<input type="radio"/>	<input type="radio"/>
nerves or feeling anxious or on edge	<input type="radio"/>	<input type="radio"/>
stomach pain	<input type="radio"/>	<input type="radio"/>

dizziness	<input type="radio"/>	<input type="radio"/>
worrying about a lot of different things	<input checked="" type="radio"/>	<input checked="" type="radio"/>
back pain	<input type="radio"/>	<input type="radio"/>
fainting spells	<input checked="" type="radio"/>	<input checked="" type="radio"/>
feeling your heart pound or race	<input type="radio"/>	<input type="radio"/>
lack of coordination or balance	<input checked="" type="radio"/>	<input checked="" type="radio"/>
pain in your arms, legs, or joints	<input type="radio"/>	<input type="radio"/>
loss of sensation, numbness or tingling	<input checked="" type="radio"/>	<input checked="" type="radio"/>
problems with your memory or concentration	<input type="radio"/>	<input type="radio"/>
partial or total loss of vision	<input checked="" type="radio"/>	<input checked="" type="radio"/>
partial or total loss of hearing	<input type="radio"/>	<input type="radio"/>
shortness of breath	<input checked="" type="radio"/>	<input checked="" type="radio"/>
constipation, loose bowels or diarrhoea	<input type="radio"/>	<input type="radio"/>
nausea, gas or indigestion	<input checked="" type="radio"/>	<input checked="" type="radio"/>

Source: FND Hope

▼ During the past month have you experienced...?

	Yes	No
A seizure or fit	<input type="radio"/>	<input type="radio"/>
an anxiety attack (suddenly feeling fear or panic)	<input checked="" type="radio"/>	<input checked="" type="radio"/>

Source: FND Hope

▼ Movement symptoms

When you have finished this question, please manually scroll back to the top of the survey to see the next question.

	Frequently (daily)	Occasionally (several times a month)	Rarely	Never
Muscle spasms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Episodic paralysis with loss of sensation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Episodic paralysis with continued sensation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paralysis - continuous (one side, upper, lower or full body)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dystonia - involuntary muscle contractions that cause slow repetitive movements or abnormal postures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Myoclonus - sudden, involuntary jerking of a muscle or group of muscles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tremor - temporary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tremor - continuous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uncomfortable, sometimes painful, sensation occurring within the limb or body rather than on the skin; often described as tingling, jitteriness, âcreepy crawlÿ, or zinging sensation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tic(s) - habitual spasmodic contraction of the muscles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gait disturbances (difficulty walking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seizures without loss of consciousness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seizures with loss of consciousness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stroke-like symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eye movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Facial pulling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: FND Hope

▼ Autonomic Dysfunction

	Frequently (daily)	Occasionally (several times a month)	Rarely	Never
Orthostatic Intolerance (inability to remain upright)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drop attacks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low Blood Pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lightheadedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Noise/light sensitivity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Temperature Regulation Problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: FND Hope

Other Symptoms

When you have finished this question, please manually scroll back to the top of the survey to see the next question.

	Frequently (daily)	Occasionally (several times a month)	Rarely	Never
Incontinence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frequent Urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Urinary retention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Numbness/neuropathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensation of electrical shocks or pin pricks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aches in joints	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aches in muscles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in taste	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dry eye	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dry mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multiple Chemical Sensitivity (MCS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smelling strange smells	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep apnea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Excessive yawning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insomnia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Excessive Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercise Intolerance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Foreign Accent Syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty having blood drawn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: FND Hope

Do you experience any other symptoms of FND that were not listed previously?

Please note that any symptoms of conditions that are not FND will be covered in a subsequent section on Comorbid Conditions.

☐ Yes
 ☐ No

What other symptoms of FND that were not listed previously do you experience?

Please list the symptom(s), followed by the frequency (frequently, occasionally, rarely, never) in parentheses.

Source: FND Hope

Course of Illness

Illness course over time has been:

☐ Stable
☐ Improved
☐ Worsening
☐ Waxing and waning

Source: FND Hope

Treatment

Treatment

Treatment Providers

Which type of health care professionals have you seen for TREATMENT of functional symptoms?

☐ Physical/physio therapist
☐ FND In-Patient Treatment Center
☐ Primary Care Physician/General Practitioner
☐ Neurologist - General Neurologist
☐ Neurologist - Movement disorders specialist
☐ Neurologist - Neuromuscular specialist
☐ Neurologist - Epilepsy specialist
☐ Neurologist - Stroke specialist
☐ Neurologist - Other
☐ Psychiatrist/Neuropsychiatrist
☐ Psychologist
☐ Other
☐ Alternative Care

Source: FND Hope

▼ What treatment have you received and how helpful has it been?

	Very helpful	Somewhat helpful	Indeterminate	Somewhat unhelpful	Harmful	Not applicable
Medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supplementation (vitamins, herbs, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physio/Physical Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behavioral Therapies (including CBT and/or DBT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talk Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meditation/Mindfulness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hypnotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breathing exercises	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biofeedback/Neurofeedback	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: FND Hope

▼ How often do you see a medical professional for FND related care?

- ☐ Weekly
- ☐ Twice a Month
- ☐ Monthly
- ☐ Every Two Months
- ☐ Quarterly
- ☐ Twice a Year
- ☐ Yearly
- ☐ None

Source: FND Hope

▼ Have you ever foregone care when you needed it because you knew medical professionals would be unable to help you?

- ☐ Yes
- ☐ No

Source: FND Hope

▼ Medications

▼ About this section...

Next we'll ask you about the drugs or medications you take.

Click **Continue** to get started...

► I currently take the following medications...

Source: Genetic Alliance PEER

Comorbid Conditions

▼ Co-morbid conditions

The presence of more than one chronic disease or condition in a patient is known as comorbidity. Do you have any diagnosed comorbid illness(es)? Below is a list of common comorbidities seen in patients with FND. Please check those that are applicable to you.

☐

Autonomic Disorder (i.e. POTS)

☐

Autoimmune, Other

☐

Bipolar Disorder

☐

Celiac Disease

☐

Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME)/Fibromyalgia

☐

Complex Regional Pain Syndrome (CRPS)

☐

Degenerative disc disease/spinal surgeries

☐

Ehlers-Danlos Syndrome (EDS)

☐

Epilepsy

☐

Iron Deficiency Anemia

☐

Irritable bowel syndrome (IBS)

☐

Migraines

☐

Raynaud's Phenomenon

☐

Stroke

☐

Thyroid Dysfunction

☐

Vitamin deficiencies such as b12 and D

☐

None

Source: Source: FND Hope

Other Co-morbid Conditions Introduction

If you have any other health conditions besides FND and those just marked previously, please enter the names in the upcoming questions. Many conditions will pop up as you begin typing. Others you will have to add. For example, you may type diabetes and select from the list. You may also want to pernicious anemia and find it does not auto-populate. In that case, simply type the full name, ensuring spelling is correct, and hit enter.

Other Conditions

I am living with a condition or health concern *other than* those I've already been asked about...

☐ Yes

☐ Did in the past

☐ No

☐ Don't know

I currently have the following other conditions or health concerns...

Please provide a list of the health conditions that you currently experience:

Start by typing a few characters and we will provide you with some possibilities. Once found, press ENTER. If the condition is not found, please complete the correct spelling of the condition, and hit ENTER to add the response.

Source: Genetic Alliance PEER

Follow-Up Survey

Fatigue Severity Scale

▼ Fatigue Severity Scale

▼ My motivation is lower when I am fatigued...

1

7

0

Strongly Disagree

Strongly Agree

▼ I am easily fatigued...

1

7

0

Strongly Disagree

Strongly Agree

▼ Fatigue interferes with my physical functioning...

1

7

0

Strongly Disagree

Strongly Agree

▼ Fatigue causes frequent problems for me...

A horizontal slider scale from 1 to 7. The left end is labeled '1' and 'Strongly Disagree'. The right end is labeled '7' and 'Strongly Agree'. There are tick marks at 1, 3, 5, and 7. A grey slider bar is positioned at 0, with a small grey square at the left end. To the right of the slider bar is a text input box containing the number '0'.

Scale Point	Label	Value
1	Strongly Disagree	0
3		
5		
7	Strongly Agree	

▼ My fatigue prevents sustained physical functioning...

1 7

Strongly Disagree Strongly Agree

▼ Fatigue interferes with carrying out certain duties and responsibilities...

A horizontal slider interface for rating the statement "Fatigue interferes with carrying out certain duties and responsibilities...". The scale ranges from 1 to 7, with "Strongly Disagree" at the left end and "Strongly Agree" at the right end. A grey slider bar is positioned at the value 1. To the right of the slider bar, there is a small input box containing the number 0.

Rating	Label
1	Strongly Disagree
2	
3	
4	
5	
6	
7	Strongly Agree

▼ Fatigue is among my most disabling symptoms...

1 7

Strongly Disagree Strongly Agree

Fatigue interferes with my work, family, or social life...

1
7
0

Strongly Disagree
Strongly Agree

Source: Fatigue Severity Scale (FSS)³

Pain Intensity

Pain Intensity

In the past 7 days, on average, I would rate my pain as...

0
10
0

No pain
Worst imaginable pain

Pain Intensity

In the past 7 days, on average, my pain was...

0
10
0

No pain
Worst pain you can think of

Source: Genetic Alliance PEER - PROMIS(r) Pain Intensity instrument Short Form

Pain Interference

³ Developers were Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. Contact Lauren B. Krupp, Department of Neurology, School of Medicine, Health Sciences Center, State University of New York at Stony Brook, Stony Brook, NY 11794-8121. E-mail: Lauren.krupp@sunysb.edu.

▼ In the past 7 days, when I felt pain, it was hard for me to...

	Never	Almost never	Sometimes	Often	Almost always
Pay attention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Run	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Walk one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have fun	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Stay standing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: Genetic Alliance - PROMIS Pain Interference Short Form⁴

Sleep Disturbance

The screenshot displays the 'Sleep Disturbance' section of the PROMIS Pain Interference Short Form. It consists of four items, each with a dropdown menu and a list of response options. The first item is 'In the past 7 days, my sleep quality was...' with options: Very Poor, Poor, Fair, Good, and Very Good. The second item is 'In the past 7 days, my sleep was refreshing...' with options: Not at all, A little bit, Somewhat, Quite a bit, and Very much. The third item is 'In the past 7 days, I had a problem with my sleep...' with options: Not at all, A little bit, Somewhat, Quite a bit, and Very much. The fourth item is 'In the past 7 days, I had difficulty falling asleep...' with options: Not at all, A little bit, Somewhat, Quite a bit, and Very much. Each item has a share, edit, and delete icon in the top right corner.

▼ Sleep Disturbance

▼ In the past 7 days, my sleep quality was...

- ☐ Very Poor
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very Good

▼ In the past 7 days, my sleep was refreshing...

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

▼ In the past 7 days, I had a problem with my sleep...

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

▼ In the past 7 days, I had difficulty falling asleep...

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

⁴ Pain Interference - This instrument has been validated by PROMIS as a “stand-alone” measure of pain interference (it’s one of their adult short forms). There’s also a stand-alone pediatric version of the short form, which has been included. Depending on age of participant, adult or child version is used.

Source: Genetic Alliance - PROMIS Sleep Disturbance Short Form⁵

Environmental Exposures

▼ **Environmental Exposures**

▼ Environmental Exposures

▼ Have you ever been exposed to a biotoxin such as mold (at home, work, or school), Lyme disease, or algae blooms on water bodies?

	Know that I have	Suspect that I have	Unsure if I have
Mold	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lyme	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Algae bloom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source: abridged from survey at survivingmold.com, developed by Dr. Ritchie Shoemaker as Assessment of Chronic Inflammatory Response Syndrome (CIRS)

▼ Environmental Exposures - Shoemaker

▼ Do you have exposure to the interior building of a water damaged building and/or microbial growth based on either visible mold, the presence of musty/damp smells, or elevated levels from air sampling?

☐ Yes

☐ No




☐ Unsure

▼ Do you have samples/evidence of spore or genus and species of fungus (air test, ERMI test, etc.)

☐ Yes




☐ No

⁵ The National Institutes of Health (NIH) implemented the Patient Reported Outcomes Measurement Information System (PROMIS) more than 10 years ago. NIH created PROMIS to develop and evaluate measures to target important health outcomes across various chronic diseases.

▼ Was/is there visible microbial growth (mold)?   




☐ Yes

☐ No

▼ Is there a presence of musty smells?   




☐ Yes

☐ No

▼ Do you remember a tick bite occurring before your illness beginning?   




☐ Yes

☐ No

▼ Did you have an unexplained rash after the bite?   




☐ Yes

☐ No

▼ Did you experience flu-like illness after the bite?   

☐ Yes




☐ No

▼ Have you had a brown recluse or other poisonous spider bite?   

☐ Yes




☐ No

☐ Unknown

▼ Did you experience flu-like illness after the bite?   

☐ Yes

☐ No

▼ Did you become ill after eating fish?   

☐ Yes

☐ No

▼ Did you become ill after exposure to a body of fresh water?

☐ Yes

☐ No

▼ Did you become ill after exposure to the ocean during a 'Red Tide' or other bloom?

☐ Yes

☐ No

▼ Did you become ill after exposure an estuary fish kill?

☐ Yes

☐ No

▼ Did you become ill after exposure to a closed shell fish bed area?

☐ Yes

☐ No

Source: survey at survivingmold.com, developed by Dr. Ritchie Shoemaker as Assessment of Chronic Inflammatory Response Syndrome (CIRS)

Family History

▼ **Family History**

▼ Family History

▼ Is there a family history of neurological disorders?

☐ Yes

☐ No

☐ Unsure

▼ What was the relationship to you of the family member(s) with a neurological disorder?



- ☐ Father
- ☐ Mother
- ☐ Brother
- ☐ Sister
- ☐ Son
- ☐ Daughter
- ☐ Grandchild(ren)
- ☐ Paternal Grandfather
- ☐ Paternal Grandmother
- ☐ Maternal Grandfather
- ☐ Maternal Grandmother
- ☐ Paternal Uncle(s)
- ☐ Paternal Aunt(s)
- ☐ Maternal Uncle(s)
- ☐ Maternal Aunt(s)
- ☐ First Cousins (Father's Side)
- ☐ First Cousins (Mother's Side)

▼ What neurological diagnosis did the family member receive?



▼ Is there a family history of autoimmune disease?



- ☐ Yes
- ☐ No
- ☐ Unsure

▼ What was the relationship to you of the family member(s) with autoimmune disorder(s)?

☐ Father

☐ Mother

☐ Brother

☐ Sister

☐ Son

☐ Daughter

☐ Grandchild(ren)

☐ Paternal Grandfather

☐ Paternal Grandmother

☐ Maternal Grandfather

☐ Maternal Grandmother

☐ Paternal Uncle(s)

☐ Paternal Aunt(s)

☐ Maternal Uncle(s)

☐ Maternal Aunt(s)

☐ First Cousins (Father's Side)

☐ First Cousins (Mother's Side)

▼ What autoimmune diagnosis did the family member receive?

▼ Is there a family history of major psychiatric disorders?

☐ Yes

☐ No

☐ Unsure

▼ What was the relationship to you of the family member(s) with a major psychiatric disorder?

☐ Father

☐ Mother

☐ Brother

☐ Sister

☐ Son

☐ Daughter

☐ Grandchild(ren)

☐ Paternal Grandfather

☐ Paternal Grandmother

☐ Maternal Grandfather

☐ Maternal Grandmother

☐ Paternal Uncle(s)

☐ Paternal Aunt(s)

☐ Maternal Uncle(s)

☐ Maternal Aunt(s)

☐ First Cousins (Father's Side)

☐ First Cousins (Mother's Side)

▼ What psychiatric diagnosis did your family member receive?

▼ Is there a family history of medically unexplained symptoms?

☐ Yes

☐ No

☐ Unsure

▼ What was the relationship to you of the family member with medically unexplained symptoms?



- ☐ Father
- ☐ Mother
- ☐ Brother
- ☐ Sister
- ☐ Son
- ☐ Daughter
- ☐ Grandchild(ren)
- ☐ Paternal Grandfather
- ☐ Paternal Grandmother
- ☐ Maternal Grandfather
- ☐ Maternal Grandmother
- ☐ Paternal Uncle(s)
- ☐ Paternal Aunt(s)
- ☐ Maternal Uncle(s)
- ☐ Maternal Aunt(s)
- ☐ First Cousins (Father's Side)
- ☐ First Cousins (Mother's Side)

Source: FND Hope with list of family members from Genetic Alliance PEER

Life Event Impact Survey

Adverse Childhood Experiences (ACEs)

Life Event Impact

Introduction to Adverse Childhood Experiences (ACEs) Study

The Adverse Childhood Experiences Study (ACE Study) is a research study conducted by Kaiser Permanente health maintenance organization and the Centers for Disease Control and Prevention (CDC) in the United States. The study has demonstrated an association of adverse childhood experiences (ACEs) with health and social problems as an adult. The ACE study's results suggest that maltreatment and household dysfunction in childhood contribute to health problems decades later. These include chronic diseases such as heart disease, cancer, stroke, and diabetes that are the most common causes of death and disability in the United States. The World Health Organization remarks that the study's findings, while relating to a specific population within the United States, might reasonably be assumed to reflect similar trends in other parts of the world.

The following question requires thinking some of your adverse childhood experiences, so you may wish to chose a time to complete it when you feel emotionally prepared and have support available.

Adverse Childhood Experiences

I had a parent or other adult in the household that often or very often swore at me, insulted me, put me down, and/or humiliated me; or acted in a way that made me afraid they might physically hurt me...

I had a parent or other adult in the household that often or very often pushed, grabbed, slapped or threw something at me; or hit me so hard that I had marks or was injured...

I had an adult or a person that was at least 5 years older than me touch or fondle me or touched their body in a sexual way; or they attempted or actually had oral, anal or vaginal intercourse with me...

I often or very often felt that no one in my family loved me or thought I was important or special; or that my family didn't look out for each other, feel close to each other, or support each other...

I often or very often felt that I didn't have enough to eat, had to wear dirty clothes, and had no one to protect me; or my parents were too drunk or high to take care of me or take me to the doctor if I needed it...

My parents were separated or divorced...

My mother and/or stepmother was often or very often pushed, grabbed, slapped, or had something thrown at her; or sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something hard; or there were times when she was repeatedly hit for more than 5 minutes or threatened with a knife or gun...

I lived with someone who was a problem drinker or alcoholic, or used street drugs...

There was a household member who was depressed or mentally ill; or there was a household member who attempted suicide...

There was a member of my household that went to prison...

Source: Adverse Childhood Experiences (ACEs) Study⁶

⁶ The CDC-Kaiser Permanente Adverse Childhood Experiences (ACE) Study is one of the largest investigations of childhood abuse and neglect and later-life health and well-being. The original ACE Study was conducted at Kaiser Permanente from 1995 to 1997 with two waves of data collection. Over 17,000 Health Maintenance Organization members from Southern California receiving physical exams completed confidential surveys regarding their childhood experiences and current health status and behaviors.

Trauma

▼ Emotional Trauma

▼ Do you believe your illness is the result of psychological trauma (current or past)?

☐ Yes

☐ No

☐ Unsure

Source: FND Hope

▼ Do you consider childhood trauma to be a major factor in your illness?

☐ Yes

☐ No

☐ Unsure

Source: FND Hope

The CDC continues ongoing surveillance of ACEs by assessing the medical status of the study participants via periodic updates of morbidity and mortality data.