FND Scientific Registry Surveys

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Initial Survey

Introduction

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

Source: Genetic Alliance PEER
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

Source: FND Hope

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
### 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).
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?

1 [ ] 5 [ ] 10 [ ]

Source: FND Hope

Diagnosing Physician

I was diagnosed by: (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.
Source: FND Hope

Source: FND Hope
Impact on Life

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

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?

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

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).
Source: Generalized Anxiety Disorder -7 (GAD-7) Scale

Source: FND Hope

Symptoms

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### 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:

- [Input field for additional information]

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Source: FND Hope

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### Onset

Over what period of time did the condition develop?

- Hours
- Days
- Weeks
- Months
- Years

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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
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

### Symptoms of FND

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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>menstrual pain or problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feeling tired or having low energy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>paralysis or weakness of an arm or leg</td>
<td></td>
<td></td>
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<tr>
<td>pain or problems during sexual intercourse</td>
<td></td>
<td></td>
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<tr>
<td>trouble sleeping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>double or blurred vision</td>
<td></td>
<td></td>
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<tr>
<td>little interest or pleasure in doing things</td>
<td></td>
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<tr>
<td>difficulty swallowing or a lump in the throat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feeling down, depressed or hopeless</td>
<td></td>
<td></td>
</tr>
<tr>
<td>headaches</td>
<td></td>
<td></td>
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<tr>
<td>difficulty speaking or slurred speech</td>
<td></td>
<td></td>
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<tr>
<td>chest pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>nerves or feeling anxious or on edge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>stomach pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
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<td>----</td>
</tr>
<tr>
<td>Dizziness</td>
<td></td>
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<tr>
<td>Worrying about a lot of different things</td>
<td></td>
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<tr>
<td>Back pain</td>
<td></td>
<td></td>
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<tr>
<td>Fainting spells</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling your heart pound or race</td>
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<td></td>
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<tr>
<td>Lack of coordination or balance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain in your arms, legs, or joints</td>
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<td></td>
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<tr>
<td>Loss of sensation, numbness or tingling</td>
<td></td>
<td></td>
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<tr>
<td>Problems with your memory or concentration</td>
<td></td>
<td></td>
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<tr>
<td>Partial or total loss of vision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial or total loss of hearing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td></td>
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<tr>
<td>Constipation, loose bowels or diarrhoea</td>
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<td></td>
</tr>
<tr>
<td>Nausea, gas or indigestion</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: FND Hope

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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>A seizure or fit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>An anxiety attack (suddenly feeling fear or panic)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Frequently (daily)</th>
<th>Occasionally (several times a month)</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscle spasms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Episodic paralysis with loss of sensation</td>
<td></td>
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<tr>
<td>Episodic paralysis with continued sensation</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Paralysis - continuous (one side, upper, lower or full body)</td>
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<tr>
<td>Dystonia - involuntary muscle contractions that cause slow repetitive movements or abnormal postures</td>
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<tr>
<td>Myoklonus - sudden, involuntary jerking of a muscle or group of muscles</td>
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<tr>
<td>Tremor - temporary</td>
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<tr>
<td>Tremor - continuous</td>
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<tr>
<td>Uncomfortably, sometimes painful, sensation occurring within the limb or body rather than on the skin, often described as tingling, jitters, creepy crawly, or zinging sensation.</td>
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<tr>
<td>Tic(s) - habitual spasmodic contraction of the muscles</td>
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<tr>
<td>Gait disturbances (difficulty walking)</td>
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<tr>
<td>Seizures without loss of consciousness</td>
<td></td>
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<tr>
<td>Seizures with loss of consciousness</td>
<td></td>
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<tr>
<td>Stroke-like symptoms</td>
<td></td>
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<tr>
<td>Eye movements</td>
<td></td>
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<tr>
<td>Facial pulling</td>
<td></td>
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</tr>
</tbody>
</table>

Source: FND Hope

### Autonomic Dysfunction

<table>
<thead>
<tr>
<th>Condition</th>
<th>Frequently (daily)</th>
<th>Occasionally (several times a month)</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orthostatic Intolerance (inability to remain upright)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Drop attacks</td>
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<tr>
<td>Low Blood Pressure</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Lightheadedness</td>
<td></td>
<td></td>
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<tr>
<td>Noise/light sensitivity</td>
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<tr>
<td>Temperature Regulation Problems</td>
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</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequently (Daily)</th>
<th>Occasionally (several times a month)</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incontinence</td>
<td></td>
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<td></td>
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<tr>
<td>Frequent Urination</td>
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<tr>
<td>Urinary Retention</td>
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<tr>
<td>Numbness/neuropathy</td>
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<tr>
<td>Sensation of electrical shocks or pin pricks</td>
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<td></td>
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<tr>
<td>Aches in joints</td>
<td></td>
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<tr>
<td>Aches in muscles</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Changes in taste</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Dry eye</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dry mouth</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Multiple Chemical Sensitivity (MCS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smelling strange smells</td>
<td></td>
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<tr>
<td>Sleep apnea</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excessive yawning</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Insomnia</td>
<td></td>
<td></td>
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<tr>
<td>Excessive Fatigue</td>
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<tr>
<td>Exercise Intolerance</td>
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<tr>
<td>Foreign Accent Syndrome</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Difficulty having blood drawn</td>
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</tbody>
</table>

Source: FND Hope

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### 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

Source: FND Hope

---

### 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
Source: FND Hope

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

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Very helpful</th>
<th>Somewhat helpful</th>
<th>Indeterminate</th>
<th>Somewhat unhelpful</th>
<th>Harmful</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td></td>
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<tr>
<td>Supplementation (vitamins, herbs, etc)</td>
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<tr>
<td>Physio/Physical Therapy</td>
<td></td>
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<tr>
<td>Occupational Therapy</td>
<td></td>
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<tr>
<td>Behavioral Therapies (including CBT and/or DBT)</td>
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<td></td>
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<tr>
<td>Talk Therapy</td>
<td></td>
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<tr>
<td>Meditation/Mindfulness</td>
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<tr>
<td>Hypnotherapy</td>
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<tr>
<td>Breathing exercises</td>
<td></td>
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<tr>
<td>Biofeedback/Neurofeedback</td>
<td></td>
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</tr>
</tbody>
</table>

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

Source: Genetic Alliance PEER

Medications

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

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: 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.

Source: Genetic Alliance PEER
Follow-Up Survey

Fatigue Severity Scale

- My motivation is lower when I am fatigued...
- I am easily fatigued...
- Fatigue interferes with my physical functioning...
Fatigue

Severity Scale (FSS)

Pain Intensity

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.
**Pain Interference**

**In the past 7 days, pain interfered with my...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day to day activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work around the home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to participate in social activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household chores</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

**In the past 7 days, I felt angry when I had pain...**

- Never
- Almost Never
- Sometimes
- Often
- Almost Always

**In the past 7 days, I had trouble doing schoolwork when I had pain...**

- Never
- Almost Never
- Sometimes
- Often
- Almost Always

**In the past 7 days, I had trouble sleeping when I had pain...**

- Never
- Almost Never
- Sometimes
- Often
- Almost Always

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

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pay attention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Run</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Walk one block</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have fun</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stay standing</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Sleep Disturbance

<table>
<thead>
<tr>
<th>Sleep Disturbance</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 7 days, my sleep quality was...</td>
<td></td>
</tr>
<tr>
<td>- Very Poor</td>
<td></td>
</tr>
<tr>
<td>- Poor</td>
<td></td>
</tr>
<tr>
<td>- Fair</td>
<td></td>
</tr>
<tr>
<td>- Good</td>
<td></td>
</tr>
<tr>
<td>- Very Good</td>
<td></td>
</tr>
</tbody>
</table>

| 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        |  |

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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.
Environmental Exposures

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

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

**Family History**

<table>
<thead>
<tr>
<th>Family History</th>
</tr>
</thead>
</table>

- 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)

<table>
<thead>
<tr>
<th>Life Event Impact</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction to Adverse Childhood Experiences (ACEs) Study</td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adverse Childhood Experiences</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>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...</td>
<td></td>
</tr>
<tr>
<td>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...</td>
<td></td>
</tr>
<tr>
<td>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...</td>
<td></td>
</tr>
<tr>
<td>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...</td>
<td></td>
</tr>
<tr>
<td>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...</td>
<td></td>
</tr>
<tr>
<td>My parents were separated or divorced...</td>
<td></td>
</tr>
<tr>
<td>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...</td>
<td></td>
</tr>
<tr>
<td>I lived with someone who was a problem drinker or alcoholic, or used street drugs...</td>
<td></td>
</tr>
<tr>
<td>There was a household member who was depressed or mentally ill; or there was a household member who attempted suicide...</td>
<td></td>
</tr>
<tr>
<td>There was a member of my household that went to prison...</td>
<td></td>
</tr>
</tbody>
</table>

Source: Adverse Childhood Experiences (ACES) Study

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