What Should the NIH Study?

The NIH is interested in what the ME / CFS community has to say; what do we want the NIH to study?

Below are some areas of study important to ME / CFS patients. Rate each item's importance from 1 - 5, where 1 means very low importance, and 5 means very high importance.

At the end of each section is a place for you to write additional suggestions that were not covered in that section as well to explain why the items you ranked as important are important. Please use these areas only for information that applies to the previous section. For example, when you reach the end of the section on medications and treatments, please only make suggestions for other medications and treatments.

We know there are many items on the form. If you need to take a break, you can leave this tab open on your internet browser, and come back to it later. All questions are optional. Feel free to skip any questions for which you do not feel you have the requisite familiarity to answer.

Please only submit one form per person.

Answers will be taken up on 11:59PM EST, WEDNESDAY, JUNE 22.

These results will be gathered and sent to the NIH to represent members of the patient community #MEAction. However, the NIH also accepts feedback from individuals. Go here to learn more: https://grants.nih.gov/grants/guide/notice-files/NOT-NS-16-024.html

Thank you! Email jaime@meaction.net with any questions

This is a global survey. Responses from all countries welcome. Responses from patients, clinicians, caregiver, scientists also welcome.

* Required

IMPORTANT NOTE: Data from all *quantitative* questions in this survey received after Sunday, June 19th at 4:15PM US EST will be publicly available. By taking this survey, you agree that your raw, anonymous, quantitative data (not the qualitative/written feedback) will be made available to others who wish to analyze this dataset. *
Mark only one oval.

- o I agree

Example Question: What do you think about chocolate? *
Chocolate is a product of the roasted bean of the tree Theobroma cacao; it is used for purposes of deliciousness.
Mark only one oval.

1 2 3 4 5

Why would I eat such a thing? I can't live without it

Section 1: Medications / Treatments

1) Low-dose naltrexone (LDN)
LDN is an opiate receptor blocker; it's demonstrated some effectiveness in MS
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

2) Rituximab
a chemotherapeutic agent that destroys defective B-cells. In theory, the newly-created B-cells function more effectively. Stage I and Stage II clinical trials have shown promise.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

3) Anti-virals
If ME is virally-triggered, anti-virals such as Valcyte may be a target for study.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

4) Antibiotics
Testing antibiotics in ME may help demonstrate that pathogens cause or contribute to symptoms.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

5) Probiotics
Probiotics are gut-friendly bacteria or fungi that may help digestion, which is often dysregulated in ME
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

6) High dose antioxidants

Reactive oxidation species (ROS) are shown to be elevated in ME patients, and antioxidant levels are shown to be low. Examples of antioxidants might be Vitamin C, Coenzyme Q-10, zinc, N-acetyl cysteine, or IV glutathione
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

7) Treatments that may affect cellular respiration
Cellular respiration is a process that takes place mostly in the mitochondria. Cells use this process to create high-energy molecules. This energy then helps to fuel all cellular reactions. Examples might be Coenzyme Q-10, NAD, biotin, and creatine.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

8) Colostrum / Lactoferrin / GcMAF
These medications are macrophage activating factors, which may stimulate the body's immune response. Studies of GcMAF have been promising, but so far only have only looked at very small groups of patients.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

9) Ampligen (Rintatolimoid)
Ampligen is an immune activator that boosts germ-detecting receptors on the surface of cells
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

10) Products and reactants of methylation
e.g. methylcobalamin, riboflavin, B-vitamins, SAM-e
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

11) Intravenous gammaglobulin (IVIG)
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

12) Interferon
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

13) Anti-inflammatories
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

14) Cognitive behavioral therapy (CBT)
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

15) Graded exercise therapy (GET)
Graded exercise therapy is a structured exercise program that aims to gradually increase how long you can carry out a physical activity. This usually involves exercise that raises your heart rate, such as swimming or walking. After establishing a baseline, the length of time and the intensity of the exercise is increased.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

16) Heart rate-based physical activity and pacing
This can include appropriate exercise or exertion with the goal of staying within the energy envelope and does not trigger a crash. The goal is not to develop aerobic exercise capacity but to increase the patient's ability to utilize anaerobic energy systems by increasing strength and flexibility. Patients use a heart rate monitor to help assess and stay within their limits, while trying to expand their capacity.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

Other
What other treatments should the NIH prioritize? Please only give answers that are not included above.

OPTIONAL: thinking of the treatments you rated as important to study, please explain why they are important

Section 2: Pathogens

17) Parvovirus B19
Parvovirus B19 can be a culprit pathogen for ME/CFS. It can cause transient anemia, skin issues, and exhaustion.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

18) Epstein-Barr Virus
EBV can be a culprit pathogen for ME/CFS. It can become dormant and reactivate, and causes exhaustion and flu-like symptoms.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

19) Herpes viruses such as HHV5 (CMV), HHV6, HHV7, HSV1, or HSV2
Human herpes viruses can cause idiopathic pneumonia, and are known to infect tissue in the nervous system. They can go latent and reactivate later.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

20) Enteroviruses
Enteroviruses are a group of RNA viruses (including those causing polio and hepatitis A) that can cause respiratory and gastrointestinal infections, and can move to the central nervous system, muscles, and heart. These include Coxsackie viruses and Echoviruses.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

21) Retroviruses
Retroviridae is a family of enveloped viruses that replicate in a host cell through the process of reverse transcription. XMRV is a retrovirus
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

22) Gut microbiome in general
The gut microbiome, or the organisms that live in the gut, has been demonstrated to be dysfunctional in ME patients. Patients show fewer species of microorganisms, a greater number of disease-causing organisms, and dysregulation post-exercise.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

23) C. pneumoniae
An intracellular pathogen that can infect a wide variety of human cells including epithelial, endothelial, and smooth muscle cells as well as macrophages, monocytes, and lymphocytes. CP is an 'energy parasite' that utilizes the host cell's resources.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

24) Candida
Candida, otherwise known as 'yeast infection', has been demonstrated to cause severe fatigue.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

25) Molds
Mold exposure has been indicated to be a potential cause of or contributor to ME symptoms. Mycotoxins, the toxic substances released by molds, were found to be prevalent in patients' blood in comparison to controls.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

26) Lyme
Lyme disease is transmitted most often by tick bite and may have very similar neurological symptoms to ME patients. ME patients may have Lyme infection as well as ME.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

27) Babesia
is a malaria-like parasite that infects red blood cells; often a coinfection with Lyme. Babesia can cause flu-like symptoms, loss of appetite, nausea, fatigue, and hemolytic anemia.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

28) Bartonella
intracellular bacterial pathogen that lives in the lining of blood vessels. It is tick-borne, and a common Lyme coinfection. Neurological symptoms include blurred vision, numbness, memory loss, balance problems, and headaches.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

Other
What other pathogens should the NIH prioritize? Please only give answers that are not included above.

OPTIONAL: thinking of the pathogens you rated as important to study, please explain why they are important

Section 3: Non-pathogenic triggers

29) Physical trauma
It has been observed that ME can sometimes be triggered following physical traumas such as car accidents or surgeries
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

30) Emotional stress
One hypothesis is that emotional stress can be a factor in the onset of ME
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

31) Chemotherapy
Some cancer patients have reported developing ME after chemotherapeutic interventions
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

32) Chemicals and pesticides
Some patients remember becoming ill after a significant exposure to chemicals such as pesticides
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

33) Heavy metals
Some people feel better after reducing their load of measurable heavy metals
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

34) Pregnancy
Some patients remember becoming ill after a pregnancy
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

35) Vaccinations
Some patients remember becoming ill after receiving a vaccination
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

Other
What other non-pathogenic triggers should the NIH prioritize? Please only give answers that are not included above.

OPTIONAL: thinking of the non-pathogenic triggers you listed as important to study, please explain why they are important

Section 4: Technology / Testing

36) PET Scan

uses small amounts of a radioactive tracer to examine the brain. So far has been used to study hypoperfusion (lack of blood flow), metabolism, and to detect activated microglia, the main immune cells in the brain. Studies so far have been on a small scale.

Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

37) MRI

White-matter hyperintensities on MRI are included in Canadian Consensus Criteria as diagnostic markers. MRI can also be used to look at white matter and grey matter volume, which has been shown in small studies to be significantly different from that of healthy individuals.

Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

38) Blood volume (spectroscopic)

Patients with ME have been shown to have lower blood volume than healthy controls, which may in part explain the high incidence of orthostatic intolerance (OI) and POTS in ME patients. Spectroscopic blood volume measurements require the injection of a small amount of radioactive substance and a full-body scan.

Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

39) Metabolomics

Metabolomics is the study of the products and reactants in cellular metabolism: every 'ingredient' the cell needs to do its work, and every 'product' that is released as a result. Metabolomics has been called 'eavesdropping on the cell'.

Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

40) Pathogen Testing
Testing for specific infection-causing organisms in ME
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

41) Autonomic Panel
An autonomic panel looks for problems in the autonomic nervous system, and would include such tests as a sweat pressor test, a tilt-table test, and the Valsalva maneuver. Autonomic dysfunction has been demonstrated in ME patients.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

42) HPA Testing
Cortisol test, ACTH stimulation test, Insulin tolerance test (ITT) -- these test the function of the hypothalamic-pituitary-adrenal axis.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

43) Two-day Exercise Testing
ME/CFS patients have shown to demonstrate similar exercise capacity to sedentary controls on day 1, but to show far less ability on day 2. Exercise tests measure the function of the lung and heart and cannot be 'fooled'.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

44) Microbiota post-exercise
Small studies have shown significant changes in the number of disease-causing organisms in the blood post-exercise in ME patients.
Mark only one oval.

1 2 3 4 5

We should NOT study this It is VITAL that we study this

45) SPECT

a type of nuclear imaging test that can produces images that show how organs work. SPECT scans of the brain have been taken pre- and post-exercise in ME patients.

Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

46) Methylation Testing

The methylation cycle is a series of chemical changes that occur in the body, the primary purpose of which is to regulate neurotransmitters, regulate genetic repair and expression, and generate energy-rich molecules such as ATP. Poor methylation can negatively impact the body's ability to produce and regulate glutathione, produce high-energy molecules, regulate neurotransmitters, repair DNA, and convert serotonin to melatonin.

Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

Other

What other kinds of tests or scans should be studied?

OPTIONAL: thinking of the tests you listed as important, please explain why they are important

Section 5: Biomarkers

47) HPA Axis Biomarkers
Cortisol, ACTH, CRH, Growth hormone
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

48) ROS (reactive oxidation species)
ROS molecules are high when oxidation is high and antioxidant status is low
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

49) Natural killer cell function
Natural killer (NK) cells form part of the innate immune system. Their function involves the recognition and destruction of tumours and virally infected cells. Preliminary studies have shown NK cells to be low in some patients, and their function to be impaired in others.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

50) Metabolomic Data
Mitochondrial dysfunction markers
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

51) Immunoglobulins
IgG, IgA, IgE, IgM
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

52) Cognitive Dysfunction
Neuropsychological testing measures cognitive dysfunction.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

53) Muscular glucose uptake / insulin uptake
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

54) Glucose
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

55) Erythrocyte sedimentation rate (ESR)
Is a widely available test that measures the rate at which red blood cells settle on the bottom of a test tube. ME patients are thought to have very low ESR.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

56) Lipkin and Hornig replication study (cytokines)
Lipkin and Hornig discovered a pattern of dysregulated cytokines early in the illness, and a second pattern later on in the illness.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

Other
What other biomarkers are significant to study?

OPTIONAL: thinking of the biomarkers you listed as important, please explain why they are important

Section 6: Research gaps, emerging needs and opportunities

Aside from the pathogens, triggers, biomarkers and tests discussed on previous pages, we'd love to know more about what you think are the greatest needs and opportunities. These questions are OPTIONAL.

What are the greatest gaps in the scientific literature?

What are the greatest emerging needs?

What are the greatest opportunities?

Section 7: Challenges & Barriers to ME Research

How significant do you think are the following challenges and barriers to ME research?

57) Lack of public awareness
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

58) Lack of awareness among doctors
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

59) Lack of awareness among scientists
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

60) Difficult to attract new researchers
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

61) Inadequate funding for research
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

62) Psychosomatic model leads to bias
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

63) Severe patients are not represented in research
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

64) Study sizes too small
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

65) Poor research design or statistical analysis
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

66) Lack of harms reporting
e.g., that patients who do not complete study or suffer significant side effects are reported in final study
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

67) Availability of raw, anonymized data (open to all who ask)
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a conern

68) Lack of patient access to their own data
Mark only one oval.

1 2 3 4 5

This is NOT a conern This is DEFINITELY a concern

69) Lack of patient involvement in research design
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

70) Inconsistent or inaccurate research definitions
Mark only one oval.

1 2 3 4 5

This is NOT a concern This is DEFINITELY a concern

Other
What are other challenges / barriers to ME research?

71) How important is it to create incentives for new researchers to enter the field?
Mark only one oval.

1 2 3 4 5

NOT very important VITALLY important

72) How important is it to have patient participation in the design of research and programs?
Mark only one oval.

1 2 3 4 5

NOT very important VITALLY important

73) How important is it to have ME expert participation in the design of research and programs?
Mark only one oval.

1 2 3 4 5

NOT very important VITALLY important

74) How important is it to that the NIH significantly increase research funding?
Mark only one oval.

1 2 3 4 5

NOT very important VITALLY important

75) How important is it to use a standard research definition for NIH-funded research?
Mark only one oval.

1 2 3 4 5

NOT very important VITALLY important

76) Which criteria should the NIH use for research? (Check all that would be acceptable)
Check all that apply.

- Oxford criteria
- Fukuda criteria
- Canadian Consensus Criteria (CCC)
- International Consensus Criteria (ICC)
- Ramsay's Criteria
- Clinical criteria for Systemic Exertion Intolerance Disease (SEID)
- Study subjects should meet multiple criteria
- Other:

77) Where should ME be housed within the NIH? (Check all that would be acceptable)

Check all that apply.

- Trans-NIH working group (where it is now)
- National Institute of Neurological Disorders and Stroke (NINDS)
- National Institute of Allergy and Infectious Diseases (NIAID)
- New institute for complex neuro-immune diseases
- Office of Women's Health
- Other:

78) What should we call this disease? (Check all that would be acceptable)
Check all that apply.

- Myalgic Encephalomyelitis (ME)
- Chronic Fatigue Syndrome (CFS)
- ME/CFS
- Systemic Exertion Intolerance Disease (SEID)
- Other:

OPTIONAL: thinking of the most significant barriers, what else can the NIH do to overcome those barriers?

OPTIONAL: Anything else the NIH should know?

Section 8: Additional research questions

How important are the following research questions?

79) Contrasting recovered or near-recovered patients with patients who progressively decline
Some patients seem to recover to, if not full capacity, then near-full capacity, while others progressively decline. A third group relapses-remits. Are there genetic markers or metabolomic data that could be gathered from each set of patients and compared?
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

80) Mast cell activation disorder
Mast cell activation can cause symptoms in response to triggers such as mold, chemicals, exercise and certain foods
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

81) Psychological factors
e.g., childhood trauma, personality type, behavioral variables, somatization
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

82) Genetics of families where ME is prevalent
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

83) Future outbreaks and survivors of past outbreaks
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

84) Children with ME
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

85) Epidemiology of ME (e.g., prevalence, age, gender, ethnicity, regional variation)
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

86) The Vagus Nerve Hypothesis
The vagus nerve hypothesis states that it is the vagus nerve that is infected in patients with ME. The vagus nerve is responsible for the 'sickness response' that includes fever and malaise, and any infection there would have a significant impact on both the gut and the nervous system.
Mark only one oval.

1 2 3 4 5

We should NOT study this — It is VITAL that we study this

Section 9: What symptoms should the NIH study?

87) Post-exertional malaise
Also known as "relapse" or "crash"
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

88) Fatigue
Physical or mental exhaustion
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

89) Orthostatic intolerance
Including postural orthostatic tachycardia (POTS), orthostatic hypotension, neurally-mediated hypotension (NMH), and other forms of orthostatic intolerance. These comprise abnormal changes to blood pressure or heart rate as a result of moving from a laying or seated to a standing position.
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

90) Cognitive dysfunction
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

91) Neurosensory (e.g., sound, light, vibration sensitivity)

Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

92) Muscle fatigability
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

93) Motor disturbances (e.g., muscle weakness, twitching, poor coordination, feeling unsteady on feet, ataxia)
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

94) Persistent flu-like feelings
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

95) Pain
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

96) Sleep disturbance
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

97) Alcohol intolerance
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

98) Depression

Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

99) Anxiety
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

100) Cardiac symptoms
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

101) Neurological symptoms
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

102) Gastrointestinal symptoms
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

103) Food sensitivities
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

104) Environmental sensitivities (e.g., mold, fuel, chemicals, and other allergens)
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

105) Respiratory symptoms

Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

106) Intolerance to heat or cold
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

107) Headache and migraine
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

108) Tender lymph nodes
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

109) Sore throat
Mark only one oval.

1 2 3 4 5

It is NOT IMPORTANT to study this — It is VITAL that we study this

Other
What other symptoms are significant to study?

OPTIONAL: thinking of the symptoms you listed as important, please explain why they are important

Demographics

i) All of the following are optional questions. Scroll to the end of this page and hit "submit" to submit your survey
What describes you best?
Check all that apply.

- Patient
- Caregiver
- Clinician
- Scientist
- Other:

ii. If you are a patient, in what year did you get sick?
iii. If you are a patient, in what year were you diagnosed?
iv. In what year were you born?
v. If you are a patient, what best describes your onset?
vi. Mark only one oval.

- Acute
- Gradual
- Combination of gradual and acute

vii. If you are a patient, do you know what your triggering event was?
viii. Check all that apply.

- Epstein-Barr Virus (Mononucleosis/Glandular Fever)
- Other herpesvirus (e..g, HSV-1, HSV-2, HHV-5/CMV, HHV-6)
- Coxsackie B
- Echovirus
- Other enterovirus
- Parvovirus B19
- C. pneumoniae
- Tick-born infection
- Mold exposure
- Chemical exposure
- Vaccination
- Emotional stress
- Physical trauma
- Surgery
- Chemotherapy
- Pregnancy
- Genetics
- I don't know
- I don't know but it was a viral infection
- I don't know but it was a non-viral infection
- I don't know but it was an environmental exposure
- Other:

ix. If you are a patient, what is your current severity?
Mark only one oval.

- Recovered or nearly recovered
- Mild
- Moderate
- Severe
- Very severe

x. *Including you*, how many members of your family have or have had ME?
Mark only one oval.

- 1
- 2
- 3
- 4
- 5
- I am a researcher or clinician with no family members with ME
- Other:

xi. Gender
Mark only one oval.

- Female
- Male
- Other

xii. What best describes your ethnicity?
Check all that apply.

- European or european descent
- East Asian or East Asian descent
- South Asian or South Asian descent
- African or African descent
- Latino
- Native or Indigenous
- Arab or Arab descent
- Other:

xiii. What country are you from?

Mark only one oval.

- United States
- United Kingdom
- Canada
- Australia
- Other: