



## **Poll Everywhere Questions**

### **Questions not for public response**

**What is your name?**

**What is your email address?**

### **Demographic Questions**

**1. Where do you currently reside?**

- A. Northeastern US
- B. Southeastern US
- C. Midwestern US
- D. Southwestern US, incl. Texas
- E. California
- F. Northwest US, not including California
- G. Canada
- H. Mexico
- I. Outside of North America

**2. Do you live in:**

- A. A city
- B. A rural area
- C. A suburban area

**3. Which of the following best describes you?**

- A. I have FA
- B. I am the parent or caregiver for someone with FA

**4. At what age were you diagnosed with FA?**

- A. 0-5 yrs
- B. 6-10 yrs
- C. 11-15 yrs
- D. 16-20 yrs
- E. 21-30 yrs
- F. >30 yrs

**5. How long ago were you diagnosed with FA?**

- A. <1 yr
- B. 1-2 yrs
- C. 3-5 yrs
- D. 6-10 yrs
- E. 11- 20 yrs
- F. >21 yrs
- G. Not sure

**6. How old are you?**

- A. 0-10 yrs
- B. 11-20 yrs
- C. 21-30 yrs
- D. 31-40 yrs
- E. 41-50 yrs
- F. > 50 yrs

**Topic 1 Polling Questions**

**7. Please select the answer that best describes your stage of disability**

- A. Minimal disability. Able to run or jump.
- B. Symptoms present but mild, able to walk and capable of leading independent life.
- C. Symptoms are overt and significant. Require regular or periodic holding on to wall or another person for stability and walking.
- D. Walking requires a walker or other aid such as a service dog. Can perform several activities of daily living.
- E. Not able to walk, confined to wheelchair, Can perform some activities of daily living that do not require standing or walking.
- F. Severe disability, dependency on others for assistance with all activities of daily living.

**8. Which of the following FA-related health concerns do you/the person you care for have currently? Select ALL that apply:**

- A. Issues with balance / walking / regular falls
- B. Coordination in hands and arms and manual dexterity – e.g. difficulty grasping/gripping/holding objects, or fine motor skills
- C. Fatigue
- D. Diabetes
- E. Scoliosis (curvature of the spine)
- F. Cardiac condition – e.g. Cardiomyopathy, shortness of breath, chest pain, arrhythmia or dysrhythmia (abnormal, irregular or fast heartbeat)
- G. Choking and/or swallowing issues
- H. Vision loss
- I. Hearing loss
- J. Dysarthria/slurred speech
- K. Incontinence and/or other urinary issues and /or any bowel issues
- L. Spasticity (cramping or stiffness in legs)
- M. Pain
- N. Other

**9. Select the FA symptoms *that most impact* your daily quality of life [select up to 3].**

- A. Issues with balance / walking / regular falls
- B. Coordination in hands and arms and manual dexterity – e.g. difficulty grasping/gripping/holding objects, or fine motor skills
- C. Fatigue
- D. Diabetes
- E. Scoliosis (curvature of the spine)
- F. Cardiac condition – e.g. Cardiomyopathy, shortness of breath, chest pain, arrhythmia or dysrhythmia (abnormal, irregular or fast heartbeat)
- G. Choking and/or swallowing issues
- H. Vision loss
- I. Hearing loss
- J. Dysarthria/slurred speech
- K. Incontinence and/or other urinary issues and /or any bowel issues
- L. Spasticity (cramping or stiffness in legs)
- M. Pain
- N. Other

**10. As disease progresses, development or progression of which of the following symptoms worries you the most? Select up to 3**

- A. Balance/ ability to stand
- B. Issues with walking / regular falls
- C. Coordination in hands and arms and manual dexterity – e.g. difficulty grasping/gripping/holding objects, or fine motor skills
- D. Fatigue
- E. Diabetes
- F. Scoliosis (curvature of the spine)
- G. Cardiac condition – e.g. Cardiomyopathy, shortness of breath, chest pain, arrhythmia or dysrhythmia (abnormal, irregular or fast heartbeat)
- H. Choking and/or swallowing issues

- I. Vision loss
- J. Hearing loss
- K. Dysarthria/slurred speech
- L. Incontinence and/or other urinary issues and /or any bowel issues
- M. Spasticity (cramping or stiffness in legs)
- N. Other

**11. What specific activities of daily life are most important to you that you are NOT able to do because of FA? Select TOP 3**

- A. Moving around independently and safely, walking and standing.
- B. Manipulating small objects (e.g., a key, picking up items)
- C. Writing and typing
- D. Sitting unaided
- E. Driving
- F. Feeding oneself, cutting food and handling utensils
- G. Personal Hygiene, taking a shower, bathing or dressing independently
- H. Transferring independently (e.g. from wheelchair/scooter to bed, toilet, etc.)
- I. Communication – speaking with others and being understood
- J. Understanding conversation in noisy settings
- K. Reading books, seeing a computer screen or phone
- L. Other

**12. As a result of living with FA, which of the following social, emotional or economic consequences are most significant to you? Select up to 4**

- A. Depression and/or Anxiety
- B. Social isolation
- C. Loss of job or inability to get a job
- D. Modified work/school hours
- E. Trouble building or maintaining relationships
- F. Frustration
- G. Lack of hope for the future
- H. Loss of independence
- I. Financial difficulties
- J. Communication issues
- K. Loss of hobbies or activities
- L. Other

## **Topic 2 Polling Questions**

**13. What medications or supplements do you take now to treat symptoms of FA? Select ALL that apply**

- A. Idebenone or CoQ10
- B. Vitamin E
- C. Vitamin B3, Nicotinamide or Niacin
- D. Other supplements or vitamins not listed
- E. Muscle relaxants (e.g. Baclofen, Chlorzaxazone, Botox, medical marijuana etc.)
- F. Pain medications (e.g. Neurontin/gabapentin, Cymbalta, Lyrica, opioids etc.)
- G. Heart medications (e.g. beta blocker, ACE-inhibitor, calcium channel blocker, diuretic, anti-arrhythmic, anti-coagulant)
- H. Diabetes medications
- I. Antidepressants or anti-anxiety medications
- J. Experimental medications as a part of a clinical trial
- K. Other
- L. Nothing

**14. What are you currently doing to help manage FA or FA symptoms? Select ALL that apply**

- A. Physical therapy, including aqua or hippo therapy
- B. Stretching
- C. Exercise (cardio or strength training)
- D. Bracing (back brace for scoliosis, leg or foot braces, AFOs)
- E. Occupational therapy
- F. Speech therapy
- G. Modifications/accommodations at work/in school/at home
- H. Mental health services
- I. Use of adaptive devices
- J. Choice of diet
- K. Other
- L. Nothing

**15. Have you undergone surgery to treat or manage symptoms of FA? Select all that apply**

- A. Spinal fusion or placement of rods for scoliosis
- B. Tendon release or surgery on feet and ankles
- C. Cardiac surgery (e.g. ablation) or implanted cardiac assist device (ICD, pacemaker, LVAD)
- D. Placement of baclofen pump
- E. Other surgery
- F. No surgery

**16. In general, how much do the medications, surgeries or lifestyle changes used improve your quality of life:**

- A. No benefit
- B. Helped somewhat
- C. Helped a lot
- D. Significant benefit
- E. Not sure

**17. Which outcomes would be meaningful to you for a possible drug treatment? Select ALL that apply**

- A. Slowing/stopping of progression (even if no gain in function, symptoms won't get worse)
- B. Gain in function (e.g. energy, strength, mobility, dexterity, cardiac function, speech)
- C. Prolong life
- D. Other

**18. Which outcome is most important for a possible FA treatment? Select ONE option**

- A. Slowing/stopping of progression (even if no gain in function, symptoms won't get worse)
- B. Gain in function (e.g. energy, strength, mobility, dexterity, cardiac function, speech)
- C. Prolong life
- D. Other

**19. Which ability or symptom would you rank as *most* important for a *possible* drug treatment today? Select up to THREE options**

- A. Improved balance / walking / fewer falls
- B. Improved arm/hand function, manual dexterity
- C. Reduced fatigue
- D. Fewer diabetic issues
- E. Reduced scoliosis (curvature of the spine)
- F. Improved cardiac symptoms
- G. Improved choking and/or swallowing issues
- H. Improved vision
- I. Improved hearing
- J. Improved dysarthria/slurred speech
- K. Improved incontinence and/or other urinary issues and /or any bowel issues
- L. Reduced spasticity
- M. Reduced pain
- N. Other

**20. Which of the following factors would influence your decision to take a new medication or participate in a clinical trial or research study? Select ALL that apply**

- A. Significant risks of serious side effects such as cardiac or kidney issues
- B. Common side effects of the treatment, such as nausea, loss of appetite, headache etc.
- C. The way that treatment is administered (for example, orally, intravenously, subcutaneous, injection into the spinal cord),
- D. How long the treatment takes, whether it requires hospitalization, required doctor's visits, etc.
- E. The burden of administration, such as the need for anesthesia, radiation exposure, surgical procedure, etc.
- F. Changing my current treatment or management plan (stopping a medication or supplement, stopping exercise)
- G. Cost
- H. Travel
- I. Other
- J. None of these