

PFDD Questions for KDA Conference

Panel 1: Health Effects and Daily Impacts of KD, responding to these questions:

1. Did you have symptoms or issues related to KD prior to being diagnosed?
 - Y/N
2. What symptoms led to you seeking care or being tested for KD?
 - Narrative answer
3. How many years after you noticed these symptoms were you diagnosed with KD?
 - Narrative answer
4. What changes have you noticed over time that you can now attribute to your KD?
 - Narrative answer
5. Which KD symptoms have the most significant impact on your daily life? Check all that apply
 1. Mobility, weakness in legs
 2. Maintaining your balance while standing or falls
 3. Activities of daily living (bathing, toileting, dressing, grooming, etc.)
 4. Weakness in arms or hands, e.g. Lifting/gripping, weakness in arms and hands
 5. Swallowing difficulty or Choking
 6. Cramping
 7. Fatigue
 8. Breathing
 9. Speaking
 10. Sexual dysfunction
 11. Social engagement
 12. Emotional issues
 13. Other (describe)
6. Of the symptoms you selected, please describe the 2 or 3 that have had the most significant impact on your life and explain why?
 - Narrative answer
7. How do you cope with the most significant symptoms you described above?
 - Narrative answer
8. Are there activities important to you that you can no longer perform due to KD?
 - Y/N
9. How do you deal with them?
 - Narrative answer
10. What worries you the most about KD?
 - Narrative answer

Panel 2: Patient Perspectives on Potential Treatments for KD, responding to these questions:

1. Do you regularly see a physician regarding your KD?
 - Y/N
2. Do you or your physician use a multidisciplinary approach to help you cope with your KD? For example, do you see other health care providers and, if so, for what purposes?
 - Narrative answer
3. Are you satisfied with the care you receive for your KD? Please explain your answer.
 - Narrative answer
4. Do you do anything else to cope with your KD? If so, what (e.g. mobility devices, medications, nutraceuticals, vitamins, etc.)?
 - Narrative answer
5. How well does your approach address KD symptoms? How does it help in your daily life?
 - Narrative answer
6. Do you exercise regularly, and what type of exercise? If so, do you believe this helps with your KD symptoms?
 - Narrative answer
7. Do you think nutrition is an important part of dealing with KD?
 - Y/N
8. Please describe your diet
 - Narrative answer
9. Until a cure for KD is found, what is your view of an ideal treatment?
 - Narrative answer
10. What specific things would this ideal treatment allow you to do in your life?
 - Narrative answer
11. Assuming an ideal treatment is not available, what do you feel is the least effect that a treatment should have to make it worthwhile?
 - Narrative answer