

HELP HDSA SHARE FEEDBACK WITH THE FOOD & DRUG ADMINISTRATION

The FDA is looking to patients and families to answer questions about their disease to assist the FDA in moving forward with drug development.

The FDA has picked Huntington's disease as one of the diseases they want to study. There will be a joint meeting hosted by the FDA between October 2014 and October 2015 for Huntington's disease and Parkinson's disease, and it's vital that the voices of HD families are heard during this process.

If you are a person with HD or a caregiver of someone affected by HD, please take a few minutes to fill out this survey.

NOTE: If you are caregiving for more than one person with HD, please fill this survey out for each of the people for whom you are caregiving.

* 1. This survey is geared towards individuals with HD, individuals with JHD, caregivers of individuals with HD, and caregivers of individuals with JHD. Are you a:

- Person with JHD
- Person with HD
- Caregiver of someone with HD
- Caregiver for someone with JHD
- Caregiver for someone with HD who is now deceased
- Caregiver for someone with JHD who is now deceased

FDA Feedback: Caregiver

This portion of the survey contains questions about your loved one's symptoms. If you care for more than one individual with HD or JHD, please complete this survey for every whom you care for.

2. How old is your loved one?

3. How long has your loved one been showing any symptoms of Huntington's disease?

4. When was your loved one diagnosed with Huntington's disease?

Genetic diagnosis MM DD YYYY
 / /

Clinical diagnosis / /

5. How often does your loved one experience symptoms of Huntington's disease?

- Never
- Occasionally
- Sometimes
- Frequently
- Constantly

Other (please specify)

6. What motor symptoms of Huntington's disease does your loved one experience? (please check all that apply)

- Chorea
- Dystonia (repetitive/abnormal muscle contraction)
- Bradykinesia (slowing of voluntary movements)
- Speech impairment
- Impaired voluntary motor control
- Swallow impairment/Choking
- Gait impairment/Falls
- Incontinence
- Seizures
- Pain
- Weight loss

Other (please specify)

7. What cognitive symptoms of Huntington's disease does your loved one experience? (please check all that apply)

- Learning problems
- Implicit memory loss (memory of how to perform activity)
- Dysexecutive syndrome (difficulties in planning, prioritizing and monitoring tasks, and in multi-tasking)
- Perseveration (the uncontrolled repetition or continuation of a response-- e.g., behavior, word, thought, activity, strategy, or emotion)
- Difficulty with emotional recognition
- Difficulty with perception of time
- Difficulty with spatial perception
- Difficulty with smell identification
- Unawareness
- Decline in cognitive processing speed
- Decline in attention
- Lack of initiation
- Impulsivity
- Irritability/temper outbursts
- Impaired initiation of speech
- Disorganization of language content

Other (please specify)

8. What behavioral symptoms of Huntington's disease does your loved one experience? (please check all that apply)

- Depression
- Mania
- Obsessions and compulsions
- Delusions and hallucinations
- Apathy
- Irritability
- Anxiety
- Panic disorder
- Sexual problems
- Sleep problems
- Demoralization

Other (please specify)

9. Of all the symptoms that your loved one experiences because of Huntington's disease, which five have the most impact on his or her life? (with 1 being the most impactful)

1.
2.
3.
4.
5.

10. To what extent do your loved one's symptoms of HD impact these activities?:

	No impact at all	Some impact	A lot of impact	My loved one has lost his or her ability to do this
Falling asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staying asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleeping during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking care of family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relations with family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No impact at all	Some impact	A lot of impact	My loved one has lost his or her ability to do this
Relations with others (friends/coworkers etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household activities/errands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical activities (walking, climbing stairs, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotional well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to concentrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to multi-task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to remember	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household chores/running errands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Planning activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in family events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enjoyment of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

From the list above, describe any important activities that your loved one has trouble doing or cannot do at all because of HD. Please be specific as to how symptoms impact activities. If there are also other symptoms/activities that were not in the list above, please discuss them here.

11. Please describe your loved one's best days and worst days. Specific examples are helpful.

12. Describe how your loved one's symptoms have changed over time (please be as specific as possible).

* 13. May HDSA contact you for additional information to support the FDA learning process?

Yes

No

FDA Feedback: Past Caregiver

This portion of the survey contains questions about your loved one's symptoms.

14. How long did your loved one show symptoms of Huntington's disease?

15. When was your loved one diagnosed with Huntington's disease?

Genetic diagnosis MM DD YYYY
 / /

Clinical diagnosis / /

16. How often did your loved one experience symptoms of Huntington's disease?

- Never
- Occasionally
- Sometimes
- Frequently
- Constantly

Other (please specify)

17. What motor symptoms of Huntington's disease did your loved one experience? (please check all that apply)

- Chorea
- Dystonia (repetitive/abnormal muscle contraction)
- Bradykinesia (slowing of voluntary movements)
- Speech impairment
- Impaired voluntary motor control
- Swallow impairment/Choking
- Gait impairment/Falls
- Incontinence
- Seizures
- Pain
- Weight loss

Other (please specify)

18. What cognitive symptoms of Huntington's disease did your loved one experience? (please check all that apply)

- Learning problems
- Implicit memory loss (memory of how to perform activity)
- Dysexecutive syndrome (difficulties in planning, prioritizing and monitoring tasks, and in multi-tasking)
- Perseveration (the uncontrolled repetition or continuation of a response-- e.g., behavior, word, thought, activity, strategy, or emotion)
- Difficulty with emotional recognition
- Difficulty with perception of time
- Difficulty with spatial perception
- Difficulty with smell identification
- Unawareness
- Decline in cognitive processing speed
- Decline in attention
- Lack of initiation
- Impulsivity
- Irritability/temper outbursts
- Impaired initiation of speech
- Disorganization of language content

Other (please specify)

19. What behavioral symptoms of Huntington's disease did your loved one experience? (please check all that apply)

- Depression
- Mania
- Obsessions and compulsions
- Delusions and hallucinations
- Apathy
- Irritability
- Anxiety
- Panic disorder
- Sexual problems
- Sleep problems
- Demoralization

Other (please specify)

20. Of all the symptoms that your loved one experiences because of Huntington's disease, which five had the most impact on his or her life? (with 1 being the most impactful)

1.
2.
3.
4.
5.

21. To what extent did your loved one's symptoms of HD impact these activities?

	No impact at all	Some impact	A lot of impact	My loved one lost his or her ability to do this
Falling asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staying asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleeping during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking care of family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relations with family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No impact at all	Some impact	A lot of impact	My loved one lost his or her ability to do this
Relations with others (friends/coworkers etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household activities/Errands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical activities (walking, climbing stairs, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotional well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to concentrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to multi-task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to remember	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Planning activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in family events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enjoyment of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

From the list above, describe any important activities that your loved one had trouble doing or was unable to do at all because of HD. Please be specific as to how symptoms impacted activities. If there were also other symptoms/activities that were not in the list above, please discuss them here.

22. Please describe your loved one's best days and worst days. Specific examples are helpful.

23. Describe how your loved symptoms changed over time (please be as specific as possible).

* 24. May HDSA contact you for additional information to support the FDA learning process?

Yes

No

FDA Feedback: Person with HD

25. How old are you?

26. How long have you been showing any symptoms of Huntington's disease?

27. When were you diagnosed with Huntington's disease?

Genetic diagnosis MM DD YYYY
 / /

Clinical diagnosis / /

28. How often do you experience symptoms of Huntington's disease?

- Never
- Occasionally
- Sometimes
- Frequently
- Constantly

Other (please specify)

29. What motor symptoms of Huntington's disease do you experience? (please check all that apply)

- Chorea
- Dystonia (repetitive/abnormal muscle contraction)
- Bradykinesia (slowing of voluntary movements)
- Speech impairment
- Impaired voluntary motor control
- Swallow impairment/Choking
- Gait impairment/Falls
- Incontinence
- Seizures
- Pain
- Weight loss

Other (please specify)

30. What cognitive symptoms of Huntington's disease do you experience? (please check all that apply)

- Learning problems
- Implicit memory loss (memory of how to perform activity)
- Difficulty with emotional recognition
- Dysexecutive syndrome (difficulties in planning, prioritizing and monitoring tasks, and in multi-tasking)
- Perseveration (the uncontrolled repetition or continuation of a response-- e.g., behavior, word, thought, activity, strategy, or emotion)
- Difficulty with perception of time
- Difficulty with spatial perception
- Difficulty with smell identification
- Unawareness
- Decline in cognitive processing speed
- Decline in attention
- Lack of initiation
- Impulsivity
- Irritability/temper outbursts
- Impaired initiation of speech
- Disorganization of language content

Other (please specify)

31. What behavioral symptoms of Huntington's disease do you experience? (please check all that apply)

- Depression
- Mania
- Obsessions and compulsions
- Delusions and hallucinations
- Apathy
- Irritability
- Anxiety
- Panic disorder
- Sexual problems
- Sleep problems
- Demoralization

Other (please specify)

32. To what extent do your symptoms of HD impact your ability to do these activities?:

	No impact at all	Some impact	A lot of impact	I can no longer do this
Falling asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staying asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleeping during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking care of family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relations with family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relations with others (friends/coworkers etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household activities/Errands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical activities (walking, climbing stairs, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotional well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to concentrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to multi-task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No impact at all	Some impact	A lot of impact	I can no longer do this
Ability to remember	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Planning activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in family events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enjoyment of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

From the list above, describe any important activities that you have trouble doing or cannot do at all because of HD. Please be specific as to how symptoms impact activities. If there are also other symptoms/activities that were not in the list above, please discuss them here.

33. Of all the symptoms that you experience because of Huntington's disease, which five have the most impact on his or her life (with 1 being the most impactful)?

1.
2.
3.
4.
5.

34. How do your best days differ from your worst days?

35. Describe how your symptoms have changed over time (please be as specific as possible).

* 36. May HDSA contact you for additional information to support the FDA learning process?

Yes

No

Contact Information

37. Thank you for your willingness to share your story. HDSA may want to contact you to gain more information, or to ask additional questions. Please give us your contact information.

*** Your information will not be shared or distributed.

Name:

City:

State:

Email Address:

Phone Number:

HELP HDSA SHARE FEEDBACK WITH THE FOOD & DRUG ADMINISTRATION

The FDA is looking to patients and families to answer questions about their disease to assist the FDA in moving forward with drug development. The FDA has picked HD as one of the diseases they want to study. There will be a joint meeting for Huntington's disease and Parkinson's disease, and it's vital that the voices of HD families are heard during this process.

If you are a person with HD or JHD, a caregiver, or a past caregiver, please take a few minutes to fill out this survey. If you are caregiving for more than one person with HD, please fill this survey out for each of the people for whom you are caregiving.

THIS SURVEY WILL TAKE ABOUT 25-30 MINUTES TO COMPLETE, AND WILL NOT AUTO-SAVE, SO PLEASE DO NOT CLOSE THE BROWSER WINDOW UNTIL YOU FINISH THE SURVEY.

[Note: If you haven't yet done so, please complete our first survey at www.hdsa.org/FDAtopic1]

1. Have you completed Survey 1 on symptoms of HD?

* 2. Please tell us about yourself. Are you a:

FDA Feedback: Caregiver

3. How old is your loved one?

4. How long has your loved one been showing any symptoms of Huntington's disease?

5. When was your loved one diagnosed with Huntington's disease?

Genetic diagnosis MM DD YYYY
 / /

Clinical diagnosis / /

Cognitive Symptoms

6. What prescription medication is your loved one taking to treat deterioration in memory and thinking?

- Donepezil (Aricept)
- Rivastigmine (Exelon)
- Galantamine (Razadyne)
- Memantine (Namenda)
- My loved one is not taking medication for cognitive dysfunction

Other (please specify)

7. What non--prescription medication is your loved one taking to treat deterioration in memory and thinking?

- Huperzine A
- Gingko biloba
- My loved one is not taking non-prescription treatment for cognitive dysfunction

Other (please specify)

8. Is your loved one impacted by a lack of insight/unawareness about his or her symptoms of HD?

Impact of Unawareness

9. Please describe how unawareness affects your loved one's behavior.

10. Does unawareness make it harder for you to help your loved one manage the symptoms of HD that are treatable with medication?

If yes, please elaborate.

11. Does unawareness make it harder for you to help your loved one change the medication(s) that (s)he is taking?

If yes, please elaborate.

12. What strategies do you use to cope with unawareness?

13. Are you your loved one's healthcare proxy?

Treatment of Motor Symptoms

14. What medications is your loved one currently taking for the chorea associated with HD? (please check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> My loved one does not have chorea | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> My loved one has chorea but is not taking medication | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Fluphenazine (Prolixin) |
| <input type="checkbox"/> Tetrabenazine (Xenazine) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Risperidone (Risperdal) | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | <input type="checkbox"/> Amantadine (Symmetrel) |
| <input type="checkbox"/> Clonazepam (Klonopin) | <input type="checkbox"/> Memantine (Namenda) |
| <input type="checkbox"/> Lorazepam (Ativan) | |

Other (please specify)

15. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of chorea medication(s) .

16. Please share your feedback about any downsides to the administration of chorea medication(s).

17. Has your loved one taken other medications for the chorea associated with HD in the last five years?
(please check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> N/A | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Fluphenazine (Prolixin) |
| <input type="checkbox"/> Tetrabenazine (Xenazine) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Risperidone (Risperdal) | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | <input type="checkbox"/> Amantadine (Symmetrel) |
| <input type="checkbox"/> Clonazepam (Klonopin) | <input type="checkbox"/> Memantine (Namenda) |
| <input type="checkbox"/> Lorazepam (Ativan) | |

Other (please specify)

18. How well do your loved one's medications manage his or her symptoms of chorea?

Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in his/her daily life. Please provide examples.

19. Please share how the treatment for your loved one's chorea symptoms has changed over time.

20. What non-prescription interventions does your loved one use to manage chorea?

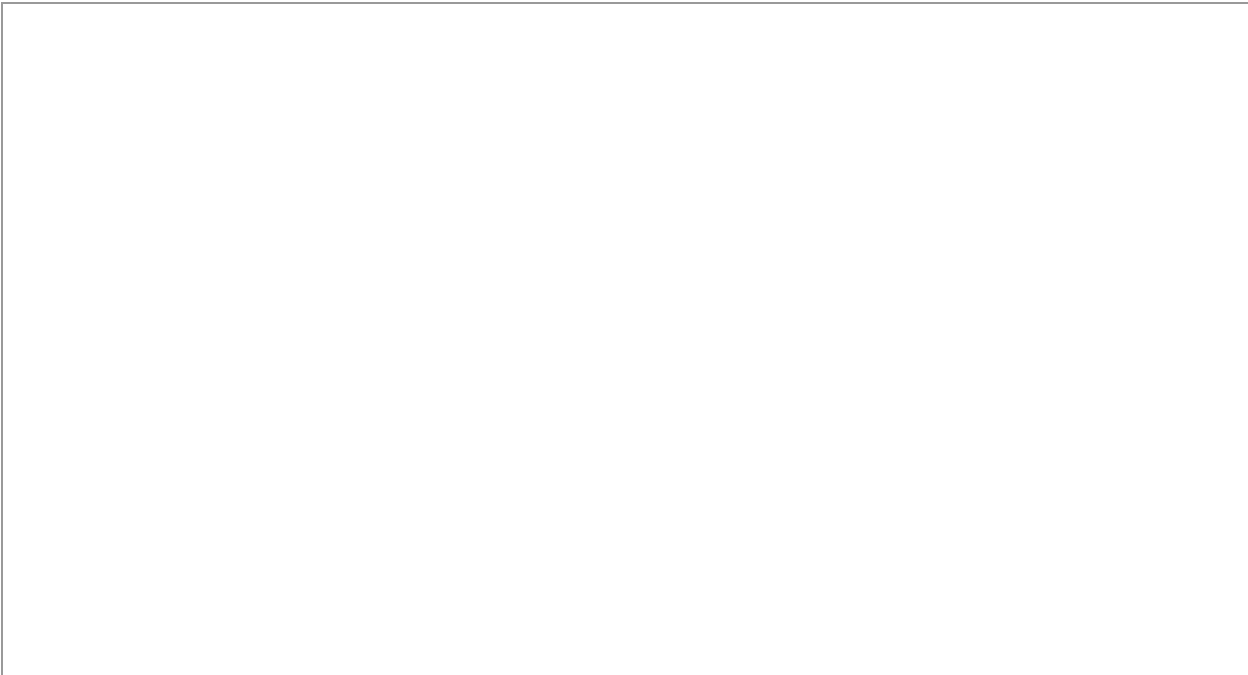
- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

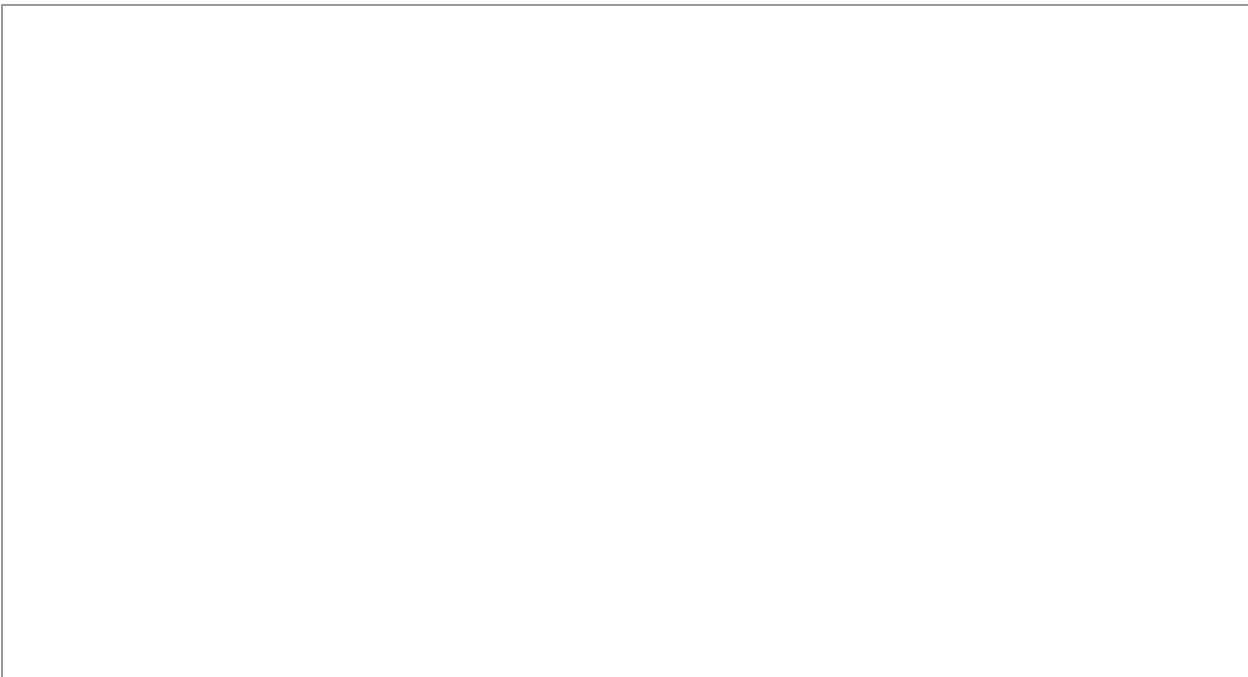
21. How well do the non-prescription interventions work to treat/manage the chorea associated with HD?

Other (please specify)

22. What characteristics would the perfect drug for chorea have? Please be specific.



23. If there could be one advancement in the area of movement disorder medications, what would you like it to be?



Treatment of Behavioral/Mood Symptoms

24. What medications is your loved one currently taking for depression? (please check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> My loved one is not being treated for depression | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Fluoxetine (Prozac) | |

Other (please specify)

25. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

26. Please share your feedback about any downsides to the administration of depression medication(s).

27. What medications has your loved one taken for depression in the last 5 years? (please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> N/A | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Fluoxetine (Prozac) | |

Other (please specify)

28. How well do your loved one's medications manage his or her symptoms of depression?

Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in his/her daily life. Please provide examples.

29. Please share how the treatment for your loved one's depression symptoms has changed over time.

30. What non-prescription interventions does your loved one use to manage depression?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

31. How well do the non-prescription interventions work to treat/manage depression?

Other (please specify)

32. What characteristics would the perfect drug for depression have? Please be specific.

33. What medications is your loved one currently taking for perseveration/anxiety? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> My loved one is not being treated for anxiety | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Escitalopram (Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Buspirone (Buspar) |

Other (please specify)

34. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

35. Please share your feedback about any downsides to the administration of anxiety/perseveration medication(s).

36. Has your loved one taken other medications in the past 5 years for perseveration/anxiety? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> N/A | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Buspirone (Buspar) |

Other (please specify)

37. How well do your loved one's medications manage his or her symptoms of perseveration/anxiety?

Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in his/her daily life. Please provide examples.

38. Please share how the treatment for your loved one's perseveration/anxiety symptoms has changed over time.

39. What non-prescription interventions does your loved one use to manage perseveration/anxiety?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

40. How well do the non-prescription interventions work to treat/manage perseveration/anxiety?

Other (please specify)

41. What characteristics would the perfect drug for perseveration/anxiety have? Please be specific.

42. What medications is your loved one currently taking for irritability? (please check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> My loved one is not treated for irritability | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Risperidone (Risperdal) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Fluoxetine (Prozac) | <input type="checkbox"/> Carbamazepine (Tegretol) |
| <input type="checkbox"/> Bupropion (Wellbutrin) | <input type="checkbox"/> Mirtazapine (Remeron) |
| <input type="checkbox"/> Venlafaxine (Effexor) | <input type="checkbox"/> Propranolol (Inderal) |
| <input type="checkbox"/> Buspirone (Buspar) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | |

Other (please specify)

43. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

44. Has your loved one taken other medications in the past 5 years for irritability? (please check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Risperidone (Risperdal) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Fluoxetine (Prozac) | <input type="checkbox"/> Carbamazepine (Tegretol) |
| <input type="checkbox"/> Bupropion (Wellbutrin) | <input type="checkbox"/> Mirtazapine (Remeron) |
| <input type="checkbox"/> Venlafaxine (Effexor) | <input type="checkbox"/> Propranolol (Inderal) |
| <input type="checkbox"/> Buspirone (Buspar) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | |

Other (please specify)

45. How well do your loved one's medications manage his or her symptoms of irritability?

Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in his/her daily life. Please provide examples.

46. Please share how the treatment for your loved one's irritability symptoms has changed over time.

47. What non-prescription interventions does your loved one use to manage irritability?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

48. How well do the non-prescription interventions work to treat/manage irritability?

Other (please specify)

49. What characteristics would the perfect drug for irritability have? please be specific.

50. What medications is your loved one currently taking for apathy (lack of interest and motivation, inability to start activities, social withdrawal, and emotional flatness)? (Please check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> My loved one is not being treated for apathy | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Methylphenidate (Ritalin) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Pemoline (Cylert) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Dextroamphetamine (Dexedrine) |

Other (please specify)

51. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

52. Has your loved one taken medications in the past 5 years for apathy? (please check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Methylphenidate (Ritalin) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Pemoline (Cylert) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Dextroamphetamine (Dexedrine) |

NA (please specify)

53. How well do your loved one's medications manage his or her symptoms of apathy?

Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in his/her daily life. Please provide examples.

54. Please share how the treatment for your loved one's apathy symptoms has changed over time.

55. What non-prescription interventions does your loved one use to manage apathy?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

56. How well do the non-prescription interventions work to treat/manage apathy?

Other (please specify)

57. What characteristics would the perfect drug for apathy have? please be specific.

58. If there could be one advancement in the area of behavioral/mood disorder medications, what would you like it to be?

59. Please use this space to share any additional feedback about symptom management. If your loved one is taking medications for symptoms not listed above, please list them here.

* 60. Are you willing to be contacted by HDSA for additional information?

Yes

No

FDA Feedback: Person with Huntington's disease

61. How old are you?

62. How long have you been showing any symptoms of Huntington's disease?

63. When were you diagnosed with Huntington's disease?

Genetic diagnosis MM DD YYYY
 / /

Clinical diagnosis / /

Cognitive Symptoms

64. What prescription medication are you taking to treat deterioration in memory and thinking?

I am not taking medication for memory and thinking

Donepezil (Aricept)

Rivastigmine (Exelon)

Galantamine (Razadyne)

Memantine (Namenda)

Other (please specify)

65. What non--prescription medication are you taking to treat deterioration in memory and thinking?

I am not taking non-prescription treatment for problems with memory and thinking

Huperzine A

Gingko biloba

Other (please specify)

Treatment of Motor Symptoms

66. What medications are you currently taking for the chorea associated with HD? (Please check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> I do not have chorea | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> I have chorea but am not taking medication | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Fluphenazine (Prolixin) |
| <input type="checkbox"/> Tetrabenazine (Xenazine) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Risperidone (Risperdal) | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | <input type="checkbox"/> Amantadine (Symmetrel) |
| <input type="checkbox"/> Clonazepam (Klonopin) | <input type="checkbox"/> Memantine (Namenda) |
| <input type="checkbox"/> Lorazepam (Ativan) | |

Other (please specify)

67. How well do your medications manage symptoms of chorea?

Please share how these medications have improved your abilities to do specific activities that are important in your daily life. Please provide examples.

68. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of chorea medication(s) .

69. Please share your feedback about any downsides to the administration of chorea medication(s)

70. Have you taken other medications for the chorea associated with HD in the last five years? (please check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> N/A | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Fluphenazine (Prolixin) |
| <input type="checkbox"/> Tetrabenazine (Xenazine) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Risperidone (Risperdal) | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | <input type="checkbox"/> Amantadine (Symmetrel) |
| <input type="checkbox"/> Clonazepam (Klonopin) | <input type="checkbox"/> Memantine (Namenda) |
| <input type="checkbox"/> Lorazepam (Ativan) | |

Other (please specify)

71. How well do your medications manage symptoms of chorea?

Please share how these medications have improved your abilities to do specific activities that are important in your daily life. Please provide examples.

72. Please share how the treatment for your chorea symptoms has changed over time.

73. What non-prescription intervention(s) do you use to manage chorea? (Please check all that apply)

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

74. How well do the non-prescription interventions work to treat/manage the chorea associated with HD?

Other (please specify)

75. What characteristics would the perfect drug for chorea have? please be specific.

76. If there could be one advancement in the area of movement disorder medications, what would you like it to be?

A large, empty rectangular box with a thin black border, intended for the respondent to write their answer to the question above. The box is currently blank.

Treatment of Behavioral/Mood Symptoms

77. What medications are you currently taking for depression? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> I am not being treated for depression | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Fluoxetine (Prozac) | |

Other (please specify)

78. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s) .

79. Please share your feedback about any downsides to the administration of depression medication(s).

80. What medications have you taken for depression in the last 5 years? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> N/A | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Fluoxetine (Prozac) | |

Other (please specify)

81. How well do your medications manage symptoms of depression?

Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please provide examples.

82. Please share how the treatment for your depression symptoms has changed over time.

83. What non-prescription interventions are you using to manage depression?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

84. How well do the non-prescription interventions work to treat/manage depression?

Other (please specify)

85. What characteristics would the perfect drug for depression have? Please be specific.

86. What medications are you currently taking for perseveration/anxiety? (Please check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> I am not being treated for anxiety | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Buspirone (Buspar) |

Other (please specify)

87. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s) .

88. Please share your feedback about any downsides to the administration of perseveration/anxiety medication(s).

89. Have you taken other medications in the past 5 years for perseveration/anxiety? (Please check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> N/A | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Escitalopram (Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Buspirone (Buspar) |

Other (please specify)

90. How well do your medications manage symptoms of perseveration/anxiety?

Please share how these medications have improved your ability to do specific activities that are important to your daily life. Please provide examples.

91. Please share how the treatment for your perseveration/anxiety symptoms has changed over time.

92. What non-prescription interventions do you use to manage perseveration/anxiety?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

93. How well do the non-prescription interventions work to treat/manage perseveration/anxiety?

Other (please specify)

94. What characteristics would the perfect drug for perseveration/anxiety have? Please be specific.

95. What medications are you currently taking for irritability? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> I am not being treated for irritability | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Risperidone (Risperdal) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Fluoxetine (Prozac) | <input type="checkbox"/> Carbamazepine (Tegretol) |
| <input type="checkbox"/> Bupropion (Wellbutrin) | <input type="checkbox"/> Mirtazapine (Remeron) |
| <input type="checkbox"/> Venlafaxine (Effexor) | <input type="checkbox"/> Propranolol (Inderal) |
| <input type="checkbox"/> Buspirone (Buspar) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | |

Other (please specify)

96. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s) .

97. Have you taken other medications in the past 5 years for irritability? (Please check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Risperidone (Risperdal) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Fluoxetine (Prozac) | <input type="checkbox"/> Carbamazepine (Tegretol) |
| <input type="checkbox"/> Bupropion (Wellbutrin) | <input type="checkbox"/> Mirtazapine (Remeron) |
| <input type="checkbox"/> Venlafaxine (Effexor) | <input type="checkbox"/> Propranolol (Inderal) |
| <input type="checkbox"/> Buspirone (Buspar) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | |

Other (please specify)

98. How well do your medications manage symptoms of irritability?

Please share how these medications have improved your ability to do specific activities that are important to your daily life. Please provide examples.

99. Please share how the treatment for your irritability symptoms have changed over time.

100. What non-prescription interventions do you use to manage irritability?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

101. How well do the non-prescription interventions work to treat/manage irritability?

Other (please specify)

102. What characteristics would the perfect drug for irritability have? Please be specific.

103. What medications are you currently taking for apathy (lack of interest and motivation, inability to start activities, social withdrawal, and emotional flatness)? (Please check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> I am not being treated for apathy | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Methylphenidate (Ritalin) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Pemoline (Cylert) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Dextroamphetamine (Dexedrine) |

Other (please specify)

104. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s) .

105. Have you taken other medications in the past 5 years for apathy? (Please check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Fluoxetine (Prozac) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Methylphenidate (Ritalin) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Pemoline (Cylert) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Dextroamphetamine (Dexedrine) |

NA (please specify)

106. How well do your medications manage symptoms of apathy?

Please share how these medications have improved ability to do specific activities that are important to your daily life. Please provide examples.

107. Please share how the treatment for your apathy symptoms changed over time.

108. What non-prescription interventions do you use to manage apathy?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

109. How well do the non-prescription interventions work to treat/manage apathy?

Other (please specify)

110. What characteristics would the perfect drug for apathy have? Please be specific.

111. If there could be one advancement in the area of behavioral/mood disorder medications, what would you like it to be?

112. Please use this space to share any additional feedback about symptom management. If your loved one is taking medications for symptoms not listed above, please list them here.

* 113. Are you willing to be contacted by HDSA for additional information?

Yes

No

FDA Feedback: Caregiver

114. How old was your loved one when (s)he was diagnosed with HD?

115. When was your loved one diagnosed with Huntington's disease?

Genetic diagnosis MM DD YYYY
 / /

Clinical diagnosis / /

116. What year did your loved one pass away?

Cognitive Symptoms

117. What prescription medication did your loved one take to treat deterioration in memory and thinking?

- Donepezil (Aricept)
- Rivastigmine (Exelon)
- Galantamine (Razadyne)
- Memantine (Namenda)
- My loved did not take medication for cognitive dysfunction

Other (please specify)

118. What non--prescription medication did your loved one take to treat deterioration in memory and thinking?

- Huperzine A
- Gingko biloba
- My loved one did not take non-prescription treatment for cognitive dysfunction

Other (please specify)

119. Was your loved one impacted by a lack of insight/unawareness about his or her symptoms of HD?

Impact of Unawareness

120. Please describe how unawareness affected your loved one's behavior.

121. Did unawareness make it harder for you to help your loved one manage the symptoms of HD that were treatable with medication?

If yes, please elaborate.

122. Did unawareness make it harder for you to help your loved one change the medication(s) that (s)he was taking?

If yes, please elaborate.

123. What strategies did you use to cope with unawareness?

A large, empty rectangular box with a thin black border, intended for the user to write their response to the question above. It occupies the upper portion of the page.

Treatment of Motor Symptoms

124. What medications did your loved one take for the chorea associated with HD? (Please check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> My loved one did not have chorea | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> My loved one had chorea but did not take medication | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Fluphenazine (Prolixin) |
| <input type="checkbox"/> Tetrabenazine (Xenazine) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Risperidone (Risperdal) | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | <input type="checkbox"/> Amantadine (Symmetrel) |
| <input type="checkbox"/> Clonazepam (Klonopin) | <input type="checkbox"/> Memantine (Namenda) |
| <input type="checkbox"/> Lorazepam (Ativan) | |

Other (please specify)

125. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of chorea medication(s) .

126. Please share your feedback about any downsides to the administration of chorea medication(s).

127. How well did your loved one's medications manage his or her symptoms of chorea?

Please share how these medications improved your loved one's abilities to do specific activities that were important to him or her in his/her daily life. Please provide examples.

128. Please share how the treatment for your loved one's chorea symptoms changed over time.

129. What non-prescription interventions did your loved one use to manage chorea?

Diet modification

Physical activity (exercise, tai-chi, yoga, etc)

Therapy/counseling

Supplements

Religion

Spirituality/meditation

None of the above

Other (please specify)

130. How well did the non-prescription interventions work to treat/manage the chorea associated with HD?

Other (please specify)

131. What characteristics would the perfect drug for chorea have? Please be specific.

132. If there could be one advancement in the area of movement disorder medications, what would you like it to be?

A large, empty rectangular box with a thin black border, intended for the respondent to write their answer to the question above. The box is currently blank.

Treatment of Behavioral/Mood Symptoms

133. What medication(s) did your loved one take for depression? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> My loved one was not treated for depression | <input type="checkbox"/> Bupropion (Wellbutrin) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Venlafaxine (Effexor) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Escitalopram(Lexapro) | <input type="checkbox"/> Duloxetine (Cymbalta) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Desvenlafaxine (Pristiq) |
| <input type="checkbox"/> Fluoxetine (Prozac) | |

Other (please specify)

134. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

135. Please share your feedback about any downsides to the administration of depression medication(s).

136. How well did your loved one's medications manage his or her symptoms of depression?

Please share how these medications improved your loved one's abilities to do specific activities that were important to him or her in his/her daily life. Please provide examples.

137. Please share how the treatment for your loved one's depression symptoms changed over time.

138. What non-prescription interventions did your loved one use to manage depression?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

139. How well do the non-prescription interventions work to treat/manage depression?

Other (please specify)

140. What characteristics would the perfect drug for depression have? Please be specific.

141. What medications did your loved one take for perseveration/anxiety? (Please check all that apply)

My loved one was not treated for anxiety

Fluoxetine (Prozac)

I do not know

Bupropion (Wellbutrin)

Sertraline (Zoloft)

Venlafaxine (Effexor)

Citalopram (Celexa)

Desvenlafaxine (Pristiq)

Escitalopram (Lexapro)

Duloxetine (Cymbalta)

Paroxetine (Paxil)

Buspirone (Buspar)

Other (please specify)

142. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

143. Please share your feedback about any downsides to the administration of medication(s) for perseveration/anxiety.

144. How well did your loved one's medications manage his or her symptoms of perseveration/anxiety?

Please share how these medications improved your loved one's abilities to do specific activities that were important to him or her in his/her daily life. Please provide examples.

145. Please share how the treatment for your loved one's perseveration/anxiety symptoms changed over time.

146. What non-prescription interventions did your loved one use to manage perseveration/anxiety?

Diet modification

Physical activity (exercise, tai-chi, yoga, etc)

Therapy/counseling

Supplements

Religion

Spirituality/meditation

None of the above

Other (please specify)

147. How well did the non-prescription interventions work to treat/manage anxiety?

Other (please specify)

148. What characteristics would the perfect drug for anxiety have? Please be specific.

149. What medications did your loved one take for irritability? (Please check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> My loved one was not treated for irritability | <input type="checkbox"/> Quetiapine (Seroquel) |
| <input type="checkbox"/> I do not know | <input type="checkbox"/> Ziprasidone (Geodon) |
| <input type="checkbox"/> Sertraline (Zoloft) | <input type="checkbox"/> Aripiprazole (Abilify) |
| <input type="checkbox"/> Citalopram (Celexa) | <input type="checkbox"/> Haloperidol (Haldol) |
| <input type="checkbox"/> Escitalopram (Lexapro) | <input type="checkbox"/> Risperidone (Risperdal) |
| <input type="checkbox"/> Paroxetine (Paxil) | <input type="checkbox"/> Valproic Acid (Depakote) |
| <input type="checkbox"/> Fluoxetine (Prozac) | <input type="checkbox"/> Carbamazepine (Tegretol) |
| <input type="checkbox"/> Bupropion (Wellbutrin) | <input type="checkbox"/> Mirtazapine (Remeron) |
| <input type="checkbox"/> Venlafaxine (Effexor) | <input type="checkbox"/> Propranolol (Inderal) |
| <input type="checkbox"/> Buspirone (Buspar) | <input type="checkbox"/> Lamotrigine (Lamictal) |
| <input type="checkbox"/> Olanzapine (Zyprexa) | |

Other (please specify)

150. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

151. How well did your loved one's medications manage his or her symptoms of irritability?

Please share how these medications improved your loved one's abilities to do specific activities that were important to him or her in his/her daily life. Please provide examples.

152. Please share how the treatment for your loved one's irritability symptoms changed over time.

153. What non-prescription interventions did your loved one use to manage irritability?

- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

154. How well did the non-prescription interventions work to treat/manage irritability?

Other (please specify)

155. What characteristics would the perfect drug for irritability have? Please be specific.

156. What medications did your loved one take for apathy (lack of interest and motivation, inability to start activities, social withdrawal, and emotional flatness)? (Please check all that apply)

My loved one was not treated for apathy

Fluoxetine (Prozac)

I do not know

Bupropion (Wellbutrin)

Sertraline (Zoloft)

Venlafaxine (Effexor)

Citalopram (Celexa)

Methylphenidate (Ritalin)

Escitalopram(Lexapro)

Pemoline (Cylert)

Paroxetine (Paxil)

Dextroamphetamine (Dexedrine)

Other (please specify)

157. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood, etc) of the medication(s).

158. How well did your loved one's medications manage his or her symptoms of apathy?

Please share how these medications improved your loved one's abilities to do specific activities that were important to him or her in his/her daily life. Please provide examples.

159. Please share how the treatment for your loved one's apathy symptoms changed over time.

160. What non-prescription interventions did your loved one use to manage apathy?

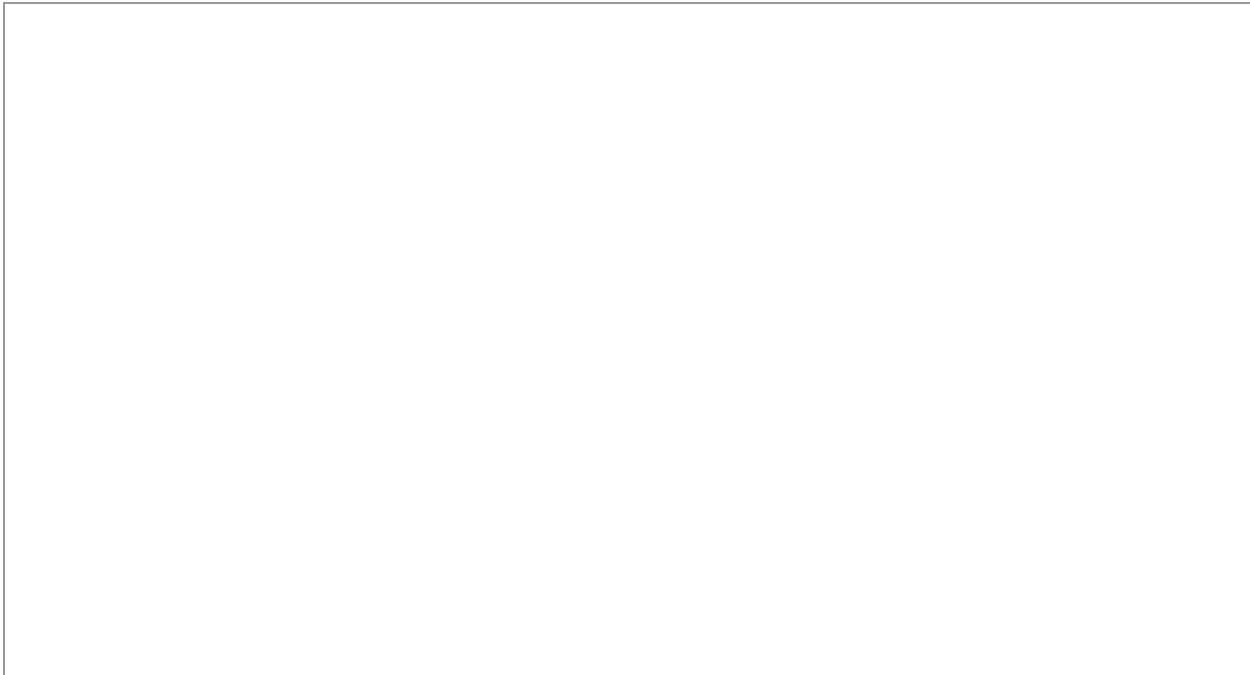
- Diet modification
- Physical activity (exercise, tai-chi, yoga, etc)
- Therapy/counseling
- Supplements
- Religion
- Spirituality/meditation
- None of the above

Other (please specify)

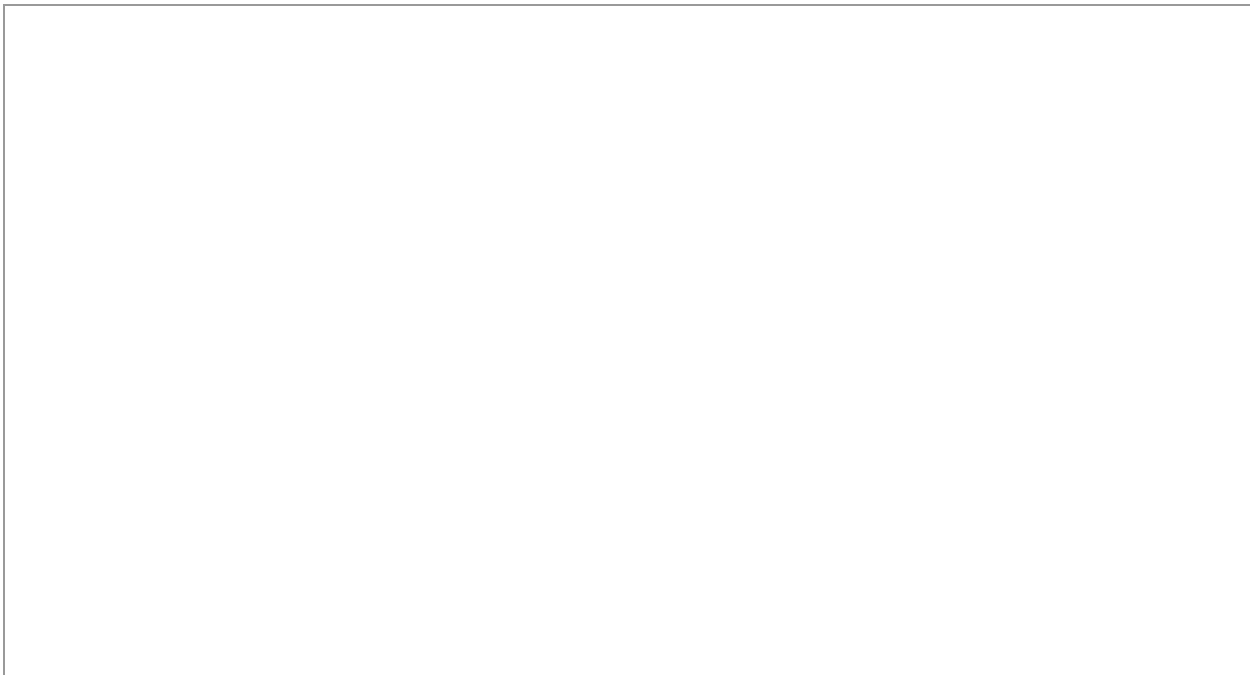
161. How well did the non-prescription interventions work to treat/manage apathy?

Other (please specify)

162. What characteristics would the perfect drug for apathy have? Please be specific.



163. If there could be one advancement in the area of behavioral/mood disorder medications, what would you like it to be?



164. Please use this space to share any additional feedback about symptom management. If your loved one is taking medications for symptoms not listed above, please list them here.

* 165. Are you willing to be contacted by HDSA for additional information?

Yes

No

Contact Information

166. Thank you for your willingness to share your story. HDSA may want to contact you to gain more information, or to ask additional questions. Please give us your contact information.

Name:

City/Town:

State:

Email Address:

Phone Number: