FDA Patient Centered Drug Development:	Topic

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.

This survey is geared towards individuals with HD, individuals with JHD, caregivers of individuals with D, 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: C	Caregiver
	e survey contains questions about your loved one's symptoms. If you care for lividual with HD or JHD, please complete this survey for every whom you care for.
2. How old is your le	
•	
3. How long has yo	ur loved one been showing any symptoms of Huntington's disease?
4. When was vour le	oved one diagnosed with Huntington's disease?
, , , , , , , , , , , , , , , , , , , ,	MM DD YYYY
Genetic diagnosis	
Clinical diagnosis	
5. How often does y	your loved one experience symptoms of Huntington's disease?
Never	
Occasionally	
Sometimes	
Frequently	
Constantly	
Other (please specify)	

6. V app	What motor symptoms of Huntington's disease does your loved one experience? (please check all that ly)
	Chorea
	Dystonia (repetitive/abnormal muscle contraction)
	Bradykynesia (slowing of voluntary movements)
	Speech impairment
	Impaired voluntary motor control
	Swallow impairment/Choking
	Gait impairment/Falls
	Incontinence
	Seizures
	Pain
	Weight loss
Othe	er (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)

Depression				
Mania				
Obsessions and comp	ulsions			
Delusions and hallucing				
Apathy				
Irritability				
Anxiety				
Panic disorder				
Sexual problems				
Sleep problems				
Demoralization				
Other (please specify)				
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he most impact on his 1. 2.			=	ease, which five have
the most impact on his 1. 2. 3. 4.	or her life? (with 1 be	eing the most impactf	ul)	ease, which five have
the most impact on his 1. 2. 3. 4.	or her life? (with 1 be	eing the most impactf	ul)	
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pecific as to how symptoms impact activities. If there are also other symptoms/activities that were not in the list above, please disc	pecific as to how symptoms impact activities. If there are also other symptoms/activities that were not in the list above, please disc	Enjoyment of life				

. Describe how	your loved one's s	symptoms have	changed over t	ime (please be a	as specific as pos	sible)
May HDSA co	ntact you for addit	ional information	on to support the	FDA learning n	rocess?	
	sor jou for addit		to support the	. D. Hoarining pi		
Yes						
No						

FDA Feedback: P	ast Caregiver
This portion of the	e survey contains questions about your loved one's symptoms.
14. How long did yo	our loved one show symptoms of Huntington's disease?
15 When was your	loved one diagnosed with Huntington's disease?
To: Whom was your	MM DD YYYY
Genetic diagnosis	
Clinical diagnosis	
16. How often did y	our loved one experience symptoms of Huntington's disease?
Never	
Occasionally	
Sometimes	
Frequently	
Constantly	
Other (please specify)	

 What motor symptoms of Huntington's disease did your loapply) 	ved one experience? (please check all that
Chorea	
Dystonia (repetitive/abnormal muscle contraction)	
Bradykynesia (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)

Depression				
Mania				
Obsessions and compl	ulsions			
Delusions and hallucing	ations			
Apathy				
Irritability				
Anxiety				
Panic disorder				
Sexual problems				
Sleep problems				
Demoralization				
Other (please specify)				
he most impact on his	-	•	=	ease, which five had
ne most impact on his	-	•	=	ease, which five had
ne most impact on his	or her life? (with 1 be	eing the most impactf	ul)	
ne most impact on his	or her life? (with 1 be	ptoms of HD impact t	hese activities?	My loved one lost his o
ne most impact on his	or her life? (with 1 be	ptoms of HD impact t	hese activities?	My loved one lost his o
he most impact on his	or her life? (with 1 be	ptoms of HD impact t	hese activities?	My loved one lost his c
he most impact on his	or her life? (with 1 be	ptoms of HD impact t	hese activities?	My loved one lost his o
Staying asleep at night Sleeping during the day	or her life? (with 1 be	ptoms of HD impact t	hese activities?	My loved one lost his o

	No impact at all	Some impact	A lot of impact	My loved one lost his o her ability to do this
Relations with others (friends/coworkers etc)	0		0	0
Employment				
Household activities/Errands				
Physical activities (walking, climbing stairs, etc)				
Emotional well-being				
Ability to concentrate	\bigcirc			
Ability to multi-task				
Ability to remember	\bigcirc			
Managing finances				
Planning activities				
Participating in family events				\circ
Oriving				
Enjoyment of life				
ease be specific as to how ease discuss them here.	symptoms impacted acti	ivities. If there were also ot	her symptoms/activities tl	nat were not in the list abo

Describe how	your loved sy	mptoms char	nged over tir	ne (please b	e as specific	as possible).	
May HDSA co	ontact you for a	additional info	ormation to s	support the F	DA learning լ	process?	
May HDSA co	ontact you for a	additional info	ormation to s	support the F	DA learning μ	process?	
Yes	ontact you for a	additional info	ormation to s	support the F	DA learning μ	process?	
	ontact you for a	additional info	ormation to s	support the F	DA learning լ	process?	
Yes	ontact you for a	additional info	ormation to s	support the F	DA learning լ	process?	

FDA Feedback:	Person with HD
25. How old are yo	ou?
26. How long have	e you been showing any symptoms of Huntington's disease?
27. When were yo	u diagnosed with Huntington's disease?
·	MM DD YYYY
Genetic diagnosis	
Clinical diagnosis	
28 How often do v	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)	
Bradykynesia (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
Othe	er (please specify)

1. What behavioral syr	mptoms of Huntingto	on's disease do you ex	(please c	heck all that apply)
Depression				
Mania				
Obsessions and compu	Isions			
Delusions and hallucina	itions			
Apathy				
Irritability				
Anxiety				
Panic disorder				
Sexual problems				
Sleep problems				
Demoralization				
other (please specify)				
	No impact at all	Some impact	do these activities?	
Falling asleen at night	No impact at all	Some impact	A lot of impact	
	No impact at all	Some impact		
Staying asleep at night	No impact at all	Some impact		
Staying asleep at night Sleeping during the day	No impact at all	Some impact		
Staying asleep at night Sleeping during the day Sex life	No impact at all	Some impact		
Staying asleep at night Sleeping during the day Sex life Taking care of family	No impact at all	Some impact		
Staying asleep at night Sleeping during the day Sex life Taking care of family Relations with family Relations with others	No impact at all	Some impact		
Staying asleep at night Sleeping during the day Sex life Taking care of family Relations with family Relations with others (friends/coworkers etc)	No impact at all	Some impact		
Staying asleep at night Sleeping during the day Sex life Taking care of family Relations with family Relations with others (friends/coworkers etc) Employment Household	No impact at all	Some impact		
Staying asleep at night Sleeping during the day Sex life Taking care of family Relations with family Relations with others (friends/coworkers etc) Employment Household activities/Errands Physical activities (walking, climbing stairs,	No impact at all	Some impact		
Falling asleep at night Staying asleep at night Sleeping during the day Sex life Taking care of family Relations with family Relations with others (friends/coworkers etc) Employment Household activities/Errands Physical activities (walking, climbing stairs, etc) Emotional well-being	No impact at all	Some impact		I can no longer do this
Staying asleep at night Sleeping during the day Sex life Taking care of family Relations with family Relations with others (friends/coworkers etc) Employment Household activities/Errands Physical activities (walking, climbing stairs, etc)	No impact at all	Some impact		

	No impact at all	Some impact	A lot of impact	I can no longer do this
Ability to remember			\bigcirc	\bigcirc
Managing finances				
Planning activities	\bigcirc			
Participating in family events				\bigcirc
Driving				
Enjoyment of life				
3. Of all the symptom	s that you experience	e because of Huntingt	on's disease, which	five have the most
	s that you experience e (with 1 being the mo	e because of Huntingtost impactful)?	on's disease, which	five have the most
			on's disease, which	five have the most
npact on his or her life			on's disease, which	five have the most
npact on his or her life			on's disease, which	five have the most
			on's disease, which	five have the most
npact on his or her life			on's disease, which	five have the most

25. Describe how your symptoms have changed over time (please be as specific as possible). 26. May HDSA contact you for additional information to support the FDA learning process? Yes No	4. How do your b	est days differ from yo	our worst days?			_
36. May HDSA contact you for additional information to support the FDA learning process? Yes						
66. May HDSA contact you for additional information to support the FDA learning process? Yes						
6. May HDSA contact you for additional information to support the FDA learning process? Yes						
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6. May HDSA contact you for additional information to support the FDA learning process? Yes						
66. May HDSA contact you for additional information to support the FDA learning process? Yes	5 Describe how	vour symptoms have (changed over time (r	olease he as specific	as nossible)	
Yes	J. Describe now		manged over time (p	——————————————————————————————————————	as possible).	7
Yes						
Yes						
Yes						
Yes						
Yes						
Yes	6 May HDCA as	ntaat van far additiona	Linformation to ounn	ort the EDA learning	nragaga?	
	_	maci you for additional	i illioimation to supp	on the FDA learning	process?	
No No	Yes					
	No					

Contact Information	า		
information, or to ask	ur willingness to share your story. H additional questions. Please give u vill not be shared or distributed.	DSA may want to contact you to gain n s your contact information.	nore
Name:			
City:			
State:	select state	<u> </u>	
Email Address:			
Phone Number:			

FDA Patient Centered Drug Development: Topic 2
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 yo	our 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 nonprescription 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?

10. Does unawareness make it harder for you to help your loved one manage the symptoms of HD that reatable with medication? [1] Yes, please elaborate. 11. Does unawareness make it harder for you to help your loved one change the medication(s) that (s) aking? [1] Yes, please elaborate.	
O. Does unawareness make it harder for you to help your loved one manage the symptoms of HD that reatable with medication? Tyes, please elaborate. 1. Does unawareness make it harder for you to help your loved one change the medication(s) that (s) taking?	
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aking?	
)he is
yes, please elaborate.	
yes, please elaborate.	
	\neg

2. What strategies	do you use to co	pe with unaware	eness? ————		_
B. Are vou vour lo	ved one's healthca	are proxy?			
		p y .			

Treatment of Motor Symptoms	
14. What medications is your loved one currently ta	king for the chorea associated with HD? (please check
My loved one does not have chorea	Haloperidol (Haldol)
My loved one has chorea but is not taking medication	Quetiapine (Seroquel)
I do not know	Fluphenazine (Prolixin)
Tetrabenazine (Xenazine)	Aripiprazole (Abilify)
Risperidone (Risperdal)	Ziprasidone (Geodon)
Olanzapine (Zyprexa)	Amantadine (Symmetrel)
Clonazepam (Klonopin)	Memantine (Namenda)
Lorazepam (Ativan)	
Other (please specify)	
16. Please share your feedback about any downsid	les to the administration of chorea medication(s).

(please check all that apply) No Haloperidol (Haldol) NA Quetiapine (Seroquel) I do not know Fluphenazine (Prolixin) Tetrabenazine (Xenazine) Artipiprazole (Abilify) Risperidone (Risperdal) Ziprasidone (Geodon) Olanzapine (Zyprexa) Amantadine (Symmetrel) Clonazepam (Klonopin) Memantine (Namenda) Lorazepam (Alivan) 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.		ns for the chorea associated with HD in the last five years?
N/A Quetiapine (Seroquel) I do not know Fluphenazine (Prolixin) Tetrabenazine (Xenazine) Aripiprazole (Abilify) Risperidone (Risperdal) Ziprasidone (Geodon) Olanzapine (Zyprexa) Amantadine (Symmetrel) Clonazepam (Klonopin) Memantine (Namenda) Lorazepam (Ativan) Other (please specify) 18. How well do your loved one's medications manage his or her symptoms of chorea?	please check all that apply)	·
I do not know Fluphenazine (Prolixin) Tetrabenazine (Xenazine) Aripiprazole (Abilify) Risperidone (Risperdal) Ziprasidone (Geodon) Olanzapine (Zyprexa) Amantadine (Symmetrel) Clonazepam (Klonopin) Memantine (Namenda) Lorazepam (Ativan) Other (please specify) 18. How well do your loved one's medications manage his or her symptoms of chorea?	No	Haloperidol (Haldol)
Tetrabenazine (Xenazine) Risperidone (Risperdal) Ziprasidone (Geodon) Amantadine (Symmetrel) Clonazepam (Klonopin) 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	N/A	Quetiapine (Seroquel)
Risperidone (Risperdal) Clanzapine (Zyprexa) Amantadine (Symmetrel) Clonazepam (Klonopin) 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	I do not know	Fluphenazine (Prolixin)
Olanzapine (Zyprexa) Amantadine (Symmetrel) Clonazepam (Klonopin) 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	Tetrabenazine (Xenazine)	Aripiprazole (Abilify)
Clonazepam (Klonopin) 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	Risperidone (Risperdal)	Ziprasidone (Geodon)
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	Olanzapine (Zyprexa)	Amantadine (Symmetrel)
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	Clonazepam (Klonopin)	Memantine (Namenda)
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	Lorazepam (Ativan)	
Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in	ther (please specify)	
Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or her in		

Diet modification				
Physical activity (exer	rcise, tai-chi, yoga, etc)			
Therapy/counseling				
Therapy/counseling Supplements				
Supplements				
Supplements				
Supplements Religion Spirituality/meditation None of the above				
Supplements Religion Spirituality/meditation None of the above				
Supplements Religion Spirituality/meditation None of the above				
Supplements Religion Spirituality/meditation None of the above other (please specify)		ntions work to trea	at/manage the cho	rea associated with HD?
Supplements Religion Spirituality/meditation None of the above other (please specify)		ntions work to trea	at/manage the cho	rea associated with HD?
Supplements Religion Spirituality/meditation None of the above Other (please specify)		ntions work to trea	at/manage the cho	rea associated with HD?
Supplements				
Supplements Religion Spirituality/meditation None of the above Other (please specify)		ntions work to trea	at/manage the cho	rea associated with HD?
Supplements Religion Spirituality/meditation None of the above Other (please specify)		ntions work to trea	at/manage the cho	rea associated with HD?

o be?				
o be?				

reatment of Behavioral/Mood Symptoms	
4. What medications is your loved one currently	taking for depression? (please check all that apply)
My loved one is not being treated for depression	Buproprion (Wellbutrin)
I do not know	Venlafaxine (Effexor)
Sertraline (Zoloft)	Valproic Acid (Depakote)
Citalopram (Celexa)	Lamotrigine (Lamictal)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Desvenlafaxine (Pristiq)
Fluoxetine (Prozac)	
other (please specify)	
5. Please share your feedback about any negattc) of the medication(s).	ive side effects (i.e. nausea, sedation, depressed mod
	ive side effects (i.e. nausea, sedation, depressed mod
tc) of the medication(s).	ive side effects (i.e. nausea, sedation, depressed mod
tc) of the medication(s).	

apply)	
αρρ.)/	
N/A	Buproprion (Wellbutrin)
I do not know	Venlafaxine (Effexor)
Sertraline (Zoloft)	Valproic Acid (Depakote)
Citalopram (Celexa)	Lamotrigine (Lamictal)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Desvenlafaxine (Pristiq)
Fluoxetine (Prozac)	
Other (please specify)	

. What non-prescription interventions	does your loved one	use to manage depr	ession?
Diet modification			
Physical activity (exercise, tai-chi, yoga, etc))		
Therapy/counseling			
Supplements			
Religion			
Spirituality/meditation			
None of the above			
ner (please specify)			
. How well do the non-prescription into	erventions work to tre	at/manage depressi	on?
ner (please specify)			

Oly) My loved one is not being treated for anxiety	Fluoxetine (Prozac)
I do not know	Buproprion (Wellbutrin)
Sertraline (Zoloft)	Venlafaxine (Effexor)
Citalopram (Celexa)	Desvenlafaxine (Pristiq)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Buspirone (Buspar)
er (please specify)	
:) of the medication(s).	ative side effects (i.e. nausea, sedation, depressed mood,
, , , , , , , , , , , , , , , , , , ,	

neck all that apply) No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Sertraline (Zoloft) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) ther (please specify) 7. How well do your loved one's medications manage his or her symptoms of perseveration/anxiety? ease share how these medications have improved your loved one's abilities to do specific activities that are important to him or		
No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Sertraline (Zoloft) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) ther (please specify) 7. How well do your loved one's medications manage his or her symptoms of perseveration/anxiety?		
No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Sertraline (Zoloft) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) ther (please specify) 7. How well do your loved one's medications manage his or her symptoms of perseveration/anxiety? ease share how these medications have improved your loved one's abilities to do specific activities that are important to him or		
No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Sertraline (Zoloft) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) ther (please specify) 7. How well do your loved one's medications manage his or her symptoms of perseveration/anxiety?		
heck all that apply) No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Sertraline (Zoloft) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) Other (please specify) 7. How well do your loved one's medications manage his or her symptoms of perseveration/anxiety?		
check all that apply) No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) Other (please specify) Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or		
check all that apply) No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) Other (please specify) Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or		
N/A		
No Fluoxetine (Prozac) N/A Buproprion (Wellbutrin) Sertraline (Zoloft) Venlafaxine (Effexor) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Buspirone (Buspar) Other (please specify) Please share how these medications have improved your loved one's abilities to do specific activities that are important to him of		edications in the past 5 years for perseveration/anxiety? (Please
N/A		
Sertraline (Zoloft) Citalopram (Celexa) Desvenlafaxine (Pristiq) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) 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		
Citalopram (Celexa) Desvenlafaxine (Pristiq) Duloxetine (Cymbalta) Paroxetine (Paxil) Dther (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	N/A	Buproprion (Wellbutrin)
Escitalopram(Lexapro) Duloxetine (Cymbalta) 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	Sertraline (Zoloft)	Venlafaxine (Effexor)
Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or	Citalopram (Celexa)	Desvenlafaxine (Pristiq)
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	Escitalopram(Lexapro)	Duloxetine (Cymbalta)
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 his/her daily life. Please provide examples.	Paroxetine (Paxil)	Buspirone (Buspar)
Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or	Other (please specify)	
Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or		
Please share how these medications have improved your loved one's abilities to do specific activities that are important to him or		
	37. How well do your loved one's med	lications manage his or her symptoms of perseveration/anxiety?
	Please share how these medications have imp	proved your loved one's abilities to do specific activities that are important to him or h

Therapy/counseling Supplements Religion	
Spirituality/meditation	
None of the above	
ther (please specify)	
0. How well do the non-prescription inte	erventions work to treat/manage perseveration/anxiety?
0. How well do the non-prescription inte	erventions work to treat/manage perseveration/anxiety?
	erventions work to treat/manage perseveration/anxiety?
0. How well do the non-prescription inte	erventions work to treat/manage perseveration/anxiety?

What medications is your loved one currer	tly taking for irritability? (please check all that apply)
My loved one is not treated for irritability	Quetiapine (Seroquel)
I do not know	Ziprasidone (Geodon)
Sertraline (Zoloft)	Aripiprazole (Abilify)
Citalopram (Celexa)	Haloperidol (Haldol)
Escitalopram(Lexapro)	Risperidone (Risperdal)
Paroxitine (Paxil)	Valproic Acid (Depakote)
Fluoxitine (Prozac)	Carbamazepine (Tegretol)
Buproprion (Wellbutrin)	Mirtazapine (Remeron)
Venlafaxine (Effexor)	Propranolol (Inderal)
Buspirone (Buspar)	Lamotrigine (Lamictal)
Olanzepine (Zyprexa)	
er (please specify)	
	_

past 5 years for irritability? (please check all that Quetiapine (Seroquel) Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol) Mirtazapine (Remeron)
Quetiapine (Seroquel) Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Quetiapine (Seroquel) Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Quetiapine (Seroquel) Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Quetiapine (Seroquel) Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Quetiapine (Seroquel) Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Ziprasidone (Geodon) Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Aripiprazole (Abilify) Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Haloperidol (Haldol) Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Risperidone (Risperdal) Valproic Acid (Depakote) Carbamazepine (Tegretol)
Valproic Acid (Depakote) Carbamazepine (Tegretol)
Carbamazepine (Tegretol)
Mirtazapine (Remeron)
Propranolol (Inderal)
Lamotrigine (Lamictal)

	ese medications have se provide examples.		one's abilities to do	specific activities that	at are important to hi	m or her
ilio/fier daily life. I lea	Se provide examples.					
6. Please share	how the treatmen	t for your loved c	one's irritability sy	mptoms has ch	anged over time.	
				<u> </u>		

47. What no	n-prescription intervent	lions does your love		inage initiability:	
Diet mod	fication				
Physical	activity (exercise, tai-chi, yog	a, etc)			
Therapy/	ounseling				
Supplem					
Religion					
	//meditation				
None of t					
Other (please	specify)				
l8. How we	I do the non-prescription	on interventions wo	rk to treat/manag	e irritability?	
Other (please	specify)				

	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? ple	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? ple	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? plea	ase be specific.	
	aracteristics would the	perfect drug for irri	tability have? ple	ase be specific.	

My loved one is not being treated for apathy	Fluoxitine (Prozac)
I do not know	Buproprion (Wellbutrin)
Sertraline (Zoloft)	Venlafaxine (Effexor)
Citalopram (Celexa)	Methylphenidate (Ritalin)
Escitalopram(Lexapro)	Pemoline (Cylert)
Paroxitine (Paxil)	Dextroamphetamine (Dexedrine)
ther (please specify)	
c) of the medication(s).	
tc) of the medication(s).	
	the past 5 years for apathy? (please check all that apply)
	the past 5 years for apathy? (please check all that apply)
2. Has your loved one taken medications in	
2. Has your loved one taken medications in	Fluoxetine (Prozac)
2. Has your loved one taken medications in No I do not know	Fluoxetine (Prozac) Buproprion (Wellbutrin)
2. Has your loved one taken medications in No I do not know Sertraline (Zoloft)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor)
2. Has your loved one taken medications in No I do not know Sertraline (Zoloft) Citalopram (Celexa)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor) Methylphenidate (Ritalin)
2. Has your loved one taken medications in No I do not know Sertraline (Zoloft) Citalopram (Celexa) Escitalopram(Lexapro)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor) Methylphenidate (Ritalin) Pemoline (Cylert)

	ese medications have ase provide examples.		one's abilities to do sp	ecific activities that a	re important to him or	r her
,	So promas shampiosi					
34. Please share	how the treatmen	t for your loved or	ne's apathy sympt	oms has change	d 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)	
6. 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.	

							_
		nptoms not			them here.		or
. Please use taking medic		nptoms not			them here.		or
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		nptoms not			them here.		or
		nptoms not			them here.		or
		nptoms not			them here.		or
taking medic	ations for syr		listed above	, please list t			or
. Are you will	ations for syr		listed above	, please list t			or
	ations for syr		listed above	, please list t			or

FDA Feedback: I	Person with Huntington's disease
61. How old are yo	u?
62. How long have	you been showing any symptoms of Huntington's disease?
63. When were you	u diagnosed with Huntington's disease?
·	MM DD YYYY
Genetic diagnosis	
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 nonprescription 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)	
Carlot (pictage speedily)	

66. What medications are you currently taking apply)	for the chorea associated with HD? (Please check all that
I do not have chorea	Haloperidol (Haldol)
I have chorea but am not taking medication	Quetiapine (Seroquel)
I do not know	Fluphenazine (Prolixin)
Tetrabenazine (Xenazine)	Aripiprazole (Abilify)
Risperidone (Risperdal)	Ziprasidone (Geodon)
Olanzapine (Zyprexa)	Amantadine (Symmetrel)
Clonazepam (Klonopin)	Memantine (Namenda)
Lorazepam (Ativan)	
Other (please specify)	
	r abilities to do specific activities that are important in your daily life. Please
Please share how these medications have improved your provide examples.	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please
	r abilities to do specific activities that are important in your daily life. Please

. Please share your feedback about a	any downsides to the administration of chorea medication(s)
Have you taken other medications fo	or the chorea associated with HD in the last five years? (please
	or the chorea associated with HD in the last five years? (please
	or the chorea associated with HD in the last five years? (please
eck all that apply)	
eck all that apply)	Haloperidol (Haldol)
eck all that apply) No N/A	Haloperidol (Haldol) Quetiapine (Seroquel)
eck all that apply) No N/A I do not know	Haloperidol (Haldol) Quetiapine (Seroquel) Fluphenazine (Prolixin)
eck all that apply) No N/A I do not know Tetrabenazine (Xenazine)	Haloperidol (Haldol) Quetiapine (Seroquel) Fluphenazine (Prolixin) Aripiprazole (Abilify)
eck all that apply) No N/A I do not know Tetrabenazine (Xenazine) Risperidone (Risperdal)	Haloperidol (Haldol) Quetiapine (Seroquel) Fluphenazine (Prolixin) Aripiprazole (Abilify) Ziprasidone (Geodon)
Peck all that apply) No N/A I do not know Tetrabenazine (Xenazine) Risperidone (Risperdal) Olanzapine (Zyprexa)	Haloperidol (Haldol) Quetiapine (Seroquel) Fluphenazine (Prolixin) Aripiprazole (Abilify) Ziprasidone (Geodon) Amantadine (Symmetrel)
Peck all that apply) No N/A I do not know Tetrabenazine (Xenazine) Risperidone (Risperdal) Olanzapine (Zyprexa) Clonazepam (Klonopin) Lorazepam (Ativan)	Haloperidol (Haldol) Quetiapine (Seroquel) Fluphenazine (Prolixin) Aripiprazole (Abilify) Ziprasidone (Geodon) Amantadine (Symmetrel)
eck all that apply) No N/A I do not know Tetrabenazine (Xenazine) Risperidone (Risperdal) Olanzapine (Zyprexa) Clonazepam (Klonopin)	Haloperidol (Haldol) Quetiapine (Seroquel) Fluphenazine (Prolixin) Aripiprazole (Abilify) Ziprasidone (Geodon) Amantadine (Symmetrel)

	your medications r	-				
lease share how throwide examples.	ese medications have	improved your abilit	ies to do specific ac	tivities that are impo	rtant in your daily life	. Please
<u> </u>						
'2 Please share	how the treatmen	t for your chores	a symntoms has	changed over tir	me	
2.1 lease share	Tiow the treatment	Tiol your choice				

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

7. What medications are you currently tak	ing for depression? (Please check all that apply)
I am not being treated for depression	Buproprion (Wellbutrin)
I do not know	Venlafaxine (Effexor)
Sertraline (Zoloft)	Valproic Acid (Depakote)
Citalopram (Celexa)	Lamotrigine (Lamictal)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Desvenlafaxine (Pristiq)
Fluoxetine (Prozac)	
Other (please specify)	
8. Please share your feedback about any etc) of the medication(s) .	negative side effects (i.e. nausea, sedation, depressed moo
	negative side effects (i.e. nausea, sedation, depressed moo
etc) of the medication(s) .	negative side effects (i.e. nausea, sedation, depressed moo
etc) of the medication(s) .	

My What medications have you taken for depression in the last 5 years? (Please check all that apply) N/A Buproprion (Wellbutrin) I do not know Venlafaxine (Effexor) Sertraline (Zoloft) Citalopram (Celexa) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Please specify) 31. 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 rovide examples.	N/A Buproprion (Wellbutrin) I do not know Venlafaxine (Effexor) Sertraline (Zoloft) Valproic Acid (Depakote) Citalopram (Celexa) Lamotrigine (Lamictal) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Desvenlafaxine (Pristiq) Sther (please specify) Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	20 What madigations have you taken for the	procesion in the last 5 years? (Please sheet; all that anniv)
I do not know	I do not know Venlafaxine (Effexor) Sertraline (Zoloft) Valproic Acid (Depakote) Citalopram (Celexa) Lamotrigine (Lamictal) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Desvenlafaxine (Pristiq) Please specify) Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please		
Sertraline (Zoloft) Valproic Acid (Depakote) Citalopram (Celexa) Lamotrigine (Lamictal) Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Desvenlafaxine (Pristiq) Pluoxetine (Prozac) Other (please specify) Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Sertraline (Zoloft)		
Citalopram (Celexa) Lamotrigine (Lamictal) Duloxetine (Cymbalta) Paroxetine (Paxil) Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Citalopram (Celexa) Lamotrigine (Lamictal) Duloxetine (Cymbalta) Paroxetine (Paxil) Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	I do not know	Venlafaxine (Effexor)
Escitalopram(Lexapro) Duloxetine (Cymbalta) Paroxetine (Paxil) Desvenlafaxine (Pristiq) Ther (please specify) 1. 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	Escitalopram(Lexapro) Duloxetine (Cymbalta) Desvenlafaxine (Pristiq) Paroxetine (Prozac) Other (please specify) 1. How well do your medications manage symptoms of depression? Desvenlafaxine (Pristiq) 1. How well do your medications manage symptoms of depression?	Sertraline (Zoloft)	Valproic Acid (Depakote)
Paroxetine (Paxil) Pluoxetine (Prozac) Ther (please specify) 1. 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	Paroxetine (Paxil) Pluoxetine (Prozac) Ther (please specify) 1. 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	Citalopram (Celexa)	Lamotrigine (Lamictal)
Ther (please specify) 1. How well do your medications manage symptoms of depression? lease share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Ther (please specify) 1. How well do your medications manage symptoms of depression? lease share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Other (please specify) 11. 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	Other (please specify) 11. 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	Paroxetine (Paxil)	Desvenlafaxine (Pristiq)
1. How well do your medications manage symptoms of depression? lease share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	1. How well do your medications manage symptoms of depression? lease share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Fluoxetine (Prozac)	
Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Other (please specify)	
Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please	Please share how these medications have improved your abilities to do specific activities that are important to your daily life. Please		
			our abilities to do specific activities that are important to your daily life. Please

t non proporintian interventions are view using to many as decrees 2	
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ion	
uality/meditation	
of the above	
ase specify)	
well do the non-prescription interventions work to treat/manage depression?	
ase specify)	
ra siit e	at non-prescription interventions are you using to manage depression? modification sical activity (exercise, tai-chi, yoga, etc) rapy/counseling plements gion ituality/meditation e of the above ease specify) v well do the non-prescription interventions work to treat/manage depression?

. What medications are you currently tak	ring for perseveration/anxiety? (Please check all that apply)
I am not being treated for anxiety	Fluoxetine (Prozac)
I do not know	Buproprion (Wellbutrin)
Sertraline (Zoloft)	Venlafaxine (Effexor)
Citalopram (Celexa)	Desvenlafaxine (Pristiq)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Buspirone (Buspar)
ner (please specify)	
Please share your feedback about anyof the medication(s).	negative side effects (i.e. nausea, sedation, depressed mood

9. Have you taken other medications	s in the past 5 years for perseveration/anxiety? (Please check all tha
oply)	
No	Fluoxetine (Prozac)
N/A	Buproprion (Wellbutrin)
Sertraline (Zoloft)	Venlafaxine (Effexor)
Citalopram (Celexa)	Desvenlafaxine (Pristiq)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Buspirone (Buspar)
her (please specify)	
The (please speedify)	
). How well do vour medications ma	nage symptoms of perseveration/anxiety?
ease share how these medications have impovide examples.	proved your ability to do specific activities that are important to your daily life. Please

	l l
2. 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 interv	ventions work to treat/manage perseveration/anxiety?
Other (please specify)	

What madigations are you currently tak	ing for irritability? (Please check all that apply)
I am not being treated for irritability	Quetiapine (Seroquel)
I do not know	Ziprasidone (Geodon)
Sertraline (Zoloft)	Aripiprazole (Abilify)
Citalopram (Celexa)	Haloperidol (Haldol)
Escitalopram(Lexapro)	Risperidone (Risperdal)
Paroxitine (Paxil)	Valproic Acid (Depakote)
Fluoxitine (Prozac)	Carbamazepine (Tegretol)
Buproprion (Wellbutrin)	Mirtazapine (Remeron)
Venlafaxine (Effexor)	Propranolol (Inderal)
Buspirone (Buspar)	Lamotrigine (Lamictal)
Olanzepine (Zyprexa)	
er (please specify)	

	the past 5 years for irritability? (Please check all that apply)
No	Quetiapine (Seroquel)
I do not know	Ziprasidone (Geodon)
Sertraline (Zoloft)	Aripiprazole (Abilify)
Citalopram (Celexa)	Haloperidol (Haldol)
Escitalopram(Lexapro)	Risperidone (Risperdal)
Paroxitine (Paxil)	Valproic Acid (Depakote)
Fluoxitine (Prozac)	Carbamazepine (Tegretol)
Buproprion (Wellbutrin)	Mirtazapine (Remeron)
Venlafaxine (Effexor)	Propranolol (Inderal)
Buspirone (Buspar)	Lamotrigine (Lamictal)
Olanzepine (Zyprexa)	
er (please specify)	

	your medications m		-			
ease share how to	nese medications have in	mproved your ability	to do specific activi	ties that are importa	nt to your daily life. F	Please
3. Please shar	e how the treatment	for your irritabili	ty symptoms ha	ve 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)	
01. 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.	

I am not being treated for apathy	Fluoxitine (Prozac)
I do not know	Buproprion (Wellbutrin)
Sertraline (Zoloft)	Venlafaxine (Effexor)
Citalopram (Celexa)	Methylphenidate (Ritalin)
Escitalopram(Lexapro)	Pemoline (Cylert)
Paroxitine (Paxil)	Dextroamphetamine (Dexedrine)
ther (please specify)	
c) of the medication(s) .	
tc) of the medication(s) .	
	s in the past 5 years for apathy? (Please check all that apply)
05. Have you taken other medication:	Fluoxetine (Prozac)
05. Have you taken other medication	
05. Have you taken other medication: No I do not know Sertraline (Zoloft)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor)
05. Have you taken other medication: No I do not know Sertraline (Zoloft) Citalopram (Celexa)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor) Methylphenidate (Ritalin)
05. Have you taken other medication: No I do not know Sertraline (Zoloft)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor)
05. Have you taken other medication: No I do not know Sertraline (Zoloft) Citalopram (Celexa)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor) Methylphenidate (Ritalin)
05. Have you taken other medication: No I do not know Sertraline (Zoloft) Citalopram (Celexa) Escitalopram(Lexapro)	Fluoxetine (Prozac) Buproprion (Wellbutrin) Venlafaxine (Effexor) Methylphenidate (Ritalin) Pemoline (Cylert)

Please share how thes	ee medications have improved ability to do specific activities that are important to your daily life. Please provi
xamples.	in medications have improved ability to do specific activities that are important to your daily life. I lease provi
07. Please share	how the treatment for your apathy symptoms changed over time.

	What non-prescription interventions do you use to manage apathy?
	iet modification
F	hysical activity (exercise, tai-chi, yoga, etc)
T	herapy/counseling
	upplements
F	eligion
s	pirituality/meditation
N	one 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.

	this space to					gement. II ye	
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						gernent. II ye	
						gernent. II ye	
						gement. II ye	
						gement. II ye	
e is taking me	edications for s	ymptoms not	listed above	, please list th	em here.	gement. II ye	
e is taking me		ymptoms not	listed above	, please list th	em here.	gement. II ye	
e is taking me	edications for s	ymptoms not	listed above	, please list th	em here.	gement. II ye	

FDA Feedback: Caregi	ver		
114 How old was your la	yed one when (c)he was dis-	annocad with HD2	
114. How old was your lov	ved one when (s)he was dia	gnosed with HD?	
115. When was your loved	d one diagnosed with Huntin	gton's disease?	
Genetic diagnosis	1 1		
Clinical diagnosis	1 1		
116. What year did your lo	oved 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 nonprescription 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?

mpact of Una	awareness	
120. Please de	scribe how unawareness affected your loved one's behavior.	
	areness make it harder for you to help your loved one manage the symptoms of HD that	
were treatable	with medication?	
fues places slab		
f yes, please elab	orate.	
122 Did upowe	areness make it harder for you to help your loved one change the medication(s) that (s)he	
vas taking?	meness make it harder for you to help your loved one change the medication(s) that (s)ne	
f yes, please elab	orate.	

s did you use to cope	with driawareness	o f 	

Treatment of Motor Symptoms	
124. What medications did your loved one take for apply)	the chorea associated with HD? (Please check all that
My loved one did not have chorea	Haloperidol (Haldol)
My loved one had chorea but did not take medication	Quetiapine (Seroquel)
I do not know	Fluphenazine (Prolixin)
Tetrabenazine (Xenazine)	Aripiprazole (Abilify)
Risperidone (Risperdal)	Ziprasidone (Geodon)
Olanzapine (Zyprexa)	Amantadine (Symmetrel)
Clonazepam (Klonopin)	Memantine (Namenda)
Lorazepam (Ativan)	
ther (please specify)	
26. Please share your feedback about any downs	sides to the administration of chorea medication(s).

	J
ease share how these s/her daily life. Please	e medications improved your loved one's abilities to do specific activities that were important to him or her in e provide examples.
o, uu,	, promos oxampios.
28. Please share	how the treatment for your loved one's chorea symptoms changed over time.

129. What no	on-prescription interventions did your loved one use to manage chorea?
Diet modif	ication
Physical a	activity (exercise, tai-chi, yoga, etc)
Therapy/c	ounseling
Suppleme	ents
Religion	
Spirituality	//meditation
None of th	ne above
Other (please s	specify)
130. How we	ell did the non-prescription interventions work to treat/manage the chorea associated with HD?
Other (please s	specify)
131 What ch	haracteristics would the perfect drug for chorea have? Please be specific.
	- and a control of the post of any serious and the post of the pos

Freatment of Behavioral/Mood Symptoms	
133. What medication(s) did your loved one tak	e for depression? (Please check all that apply)
My loved one was not treated for depression	Buproprion (Wellbutrin)
I do not know	Venlafaxine (Effexor)
Sertraline (Zoloft)	Valproic Acid (Depakote)
Citalopram (Celexa)	Lamotrigine (Lamictal)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Desvenlafaxine (Pristiq)
Fluoxetine (Prozac)	
Other (please specify)	
134. Please share your feedback about any negetc) of the medication(s).	gative side effects (i.e. nausea, sedation, depressed mood
	gative side effects (i.e. nausea, sedation, depressed mood
etc) of the medication(s).	gative side effects (i.e. nausea, sedation, depressed mood
etc) of the medication(s).	

	nese medications impr		e's abilities to do sp	pecific activities that	were important to hi	m or her in
is/her daily life. Ple	ease provide examples	5.				
37. Please sha	re how the treatm	ent for vour love	ed one's depres	sion symptoms c	hanged over tim	ie.

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)	
39. How well do the non-prescription interventions work to treat/manage depression?	
other (please specify)	
40. What characteristics would the perfect drug for depression have? Please be specific.	
+0. What characteristics would the perfect drug for depression have: Thease 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	Buproprion (Wellbutrin)
Sertraline (Zoloft)	Venlafaxine (Effexor)
Citalopram (Celexa)	Desvenlafaxine (Pristiq)
Escitalopram(Lexapro)	Duloxetine (Cymbalta)
Paroxetine (Paxil)	Buspirone (Buspar)
Other (please specify)	
143. Please share your feedback about any dow perseveration/anxiety.	vnsides to the administration of medication(s) for

lease share how these medications improved your loved one's abilities to do specific activities that were important to him is/her daily life. Please provide examples. 45. Please share how the treatment for your loved one's perseveration/anxiety symptoms changed me.	n or her ir
45. Please share how the treatment for your loved one's perseveration/anxiety symptoms changed	
me.	d over

l46. What non-pre	scription interventions did your loved one use to manage perseveration/anxiety?
Diet modification	
Physical activity (exercise, tai-chi, yoga, etc)
Therapy/counseling	ng
Supplements	
Religion	
Spirituality/medita	tion
None of the above	9
Other (please specify)	
147. How well did t	the non-prescription interventions work to treat/manage anxiety?
Other (please specify)	

149. What medications did your loved one take	e for irritability? (Please check all that apply)
My loved one was not treated for irritability	Quetiapine (Seroquel)
I do not know	Ziprasidone (Geodon)
Sertraline (Zoloft)	Aripiprazole (Abilify)
Citalopram (Celexa)	Haloperidol (Haldol)
Escitalopram(Lexapro)	Risperidone (Risperdal)
Paroxitine (Paxil)	Valproic Acid (Depakote)
Fluoxitine (Prozac)	Carbamazepine (Tegretol)
Buproprion (Wellbutrin)	Mirtazapine (Remeron)
Venlafaxine (Effexor)	Propranolol (Inderal)
Buspirone (Buspar)	Lamotrigine (Lamictal)
Olanzepine (Zyprexa)	
Other (please specify)	
	egative side effects (i.e. nausea, sedation, depressed mood,
150. Please share your feedback about any neetc) of the medication(s).	egative side effects (i.e. nausea, sedation, depressed mood,
	egative side effects (i.e. nausea, sedation, depressed mood

	these medications impro		e's abilities to do s _l	pecific activities tha	t were important to h	nim or her in
is/fici daily life. I		•				
52. Please sh	are how the treatme	ent for your love	d one's irritabili	ty symptoms ch	anged 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 interventio	ons work to treat/manage irritability?
Other (please specify)	

57. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mood to) of the medication(s). 58. How well did your loved one's medications manage his or her symptoms of apathy? lease share how these medications improved your loved one's abilities to do specific activities that were important to him or her	My loved one was not treated for apathy	Fluoxitine (Prozac)
Citalopram (Celexa) Methylphenidate (Ritalin) Escitalopram(Lexapro) Pemoline (Cylert) Paroxitine (Paxil) Dextroamphetamine (Dexedrine) Sther (please specify) Dextroamphetamine (Dexedrine) Str. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mootets) of the medication(s). Str. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mootets) of the medication(s). Str. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mootets) of the medication(s).	I do not know	Buproprion (Wellbutrin)
Escitalopram(Lexapro) Pemoline (Cylert) Dextroamphetamine (Dexedrine) Dither (please specify) 157. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed mootetc) 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	Sertraline (Zoloft)	Venlafaxine (Effexor)
Paroxitine (Paxil) Dextroamphetamine (Dexedrine) Destroamphetamine (Dexedrine)	Citalopram (Celexa)	Methylphenidate (Ritalin)
Dither (please specify) 157. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed moodetc) 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	Escitalopram(Lexapro)	Pemoline (Cylert)
157. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed moodetc) 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	Paroxitine (Paxil)	Dextroamphetamine (Dexedrine)
157. Please share your feedback about any negative side effects (i.e. nausea, sedation, depressed moodetc) 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 his/her dally life. Please provide examples.	Other (please specify)	
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		
Please share how these medications improved your loved one's abilities to do specific activities that were important to him or her		
	Please share how these medications improved your love	
	Please share how these medications improved your love	

60. What non-prescription interve	entions did vour love	d one use to mana	ge apathv?	
Diet modification	,		5 - 1 5	
Physical activity (exercise, tai-chi, yo	ga. etc)			
Therapy/counseling	g=, <i>)</i>			
Supplements				
Religion				
Spirituality/meditation				
None of the above				
her (please specify)				
1. How well did the non-prescrip	otion interventions w	ork to treat/manage	e apathy?	
her (please specify)				

	this space to share an dications for symptom			If your loved
_	ing to be contacted by	HDSA for additi	ional information?	
Yes				
No				

Contact Information	1		
	our willingness to share your story. Hadditional questions. Please give us	HDSA may want to contact you to gain more s your contact information.	
Name:			
City/Town:			
State:	select state		
Email Address:			
Phone Number:			