AUGUST 2025

Huntington's Disease Society of America

VOICE OF THE PATIENT REPORT

Living with Huntington's Disease

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This report was prepared by **The Huntington's Disease Society of America (HDSA)**, a leading national organization dedicated to the care and cure of Huntington's disease (HD)[1]a rare and fatal genetic neurological disease with mental health, cognitive, and physical components.

HDSA's focus is to promote and support research to find a cure for HD; help people and families affected by the disease; and educate the public and healthcare professionals about HD. The disease causes progressive breakdown of nerve cells in the brain, leading to death. If a parent has HD, each of their children has a 50 percent chance of inheriting HD. Currently there is no cure for HD, nor any disease modifying therapies.

This **Voice of the Patient Report** summarizes the input of members of the Huntington's disease community who bravely shared both their perspectives on the impact of living with HD and on treatments for HD during an Externally-led Patient Focused Drug Development Meeting for People Living with Pre-symptomatic, Early and Mid-stage Adult-Onset Huntington's Disease.[2]

1. *Throughout the report, Huntington's disease will be referred to as HD.*
2. *Externally-led Patient Focused Drug Development Meeting for People Living with Pre-symptomatic, Early and Mid-stage Adult-Onset Huntington's Disease will be referred to as EL-PFDD throughout the report.*

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Acknowledgements

The **Huntington's Disease Society of America (HDSA)** is deeply grateful to those individuals living with Huntington's disease (HD), their caregivers, family members, and other advocates who shared their personal stories and perspectives of the lived experiences on the day of this meeting and provided written responses to questions after the meeting. We are thankful for the panelists who spent countless hours preparing their statements and courageously sharing them during the meeting. We are grateful to **Victor Sung, M.D.** for sharing the natural history of HD with the attendees and **Elizabeth Manning** for her compassionate facilitation of the group discussions. Thank you to the many staff members of the U.S. Food and Drug Administration, medical product developers, researchers and clinicians that made the time to attend this meeting and to listen and learn. We are grateful to **Teresa Buracchio, M.D.,** Director, Office of Neuroscience, Center for Drug Evaluation and Research, Food and Drug Administration for sharing her insights during her opening remarks. And finally, we thank **Ethan Gabbour** with the Center for Drug Evaluation and Research, Food and Drug Administration for navigating HDSA through the process of hosting the EL-PFDD. It is our hope that the FDA, medical product developers, and researchers will use the voice of people with the lived experience of HD and their families to improve the lives of the HD community through the development of meaningful and impactful therapies.

ADVISORY COMMITTEE

A special thank you to the Advisory Committee for their invaluable input in planning the meeting.

- **Jenna Heilman,** Huntington's Disease Youth Organization
- **Sarah Henandez,** Hereditary Disease Foundation
- **Katie Jackson,** Help4HD
- **Betsey McFarland,** HD Reach
- **Laurel Stine**, American Foundation for Suicide Prevention
- **Jamie Sullivan,** EveryLife Foundation

CORPORATE PARTNERS

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For additional information about this report, please contact Phyllis Foxworth, HDSA's Senior Manager of Advocacy at pfoxworth@hdsa.org.

Introduction

On November 13, 2024, 146 people living with Huntington's disease and family members met in person or virtually to share their experience on the impact of living with HD and their perspectives around therapeutics to treat HD. Participants prepared for the meeting by taking the ***HDSA HD Symptoms and Treatment Impact Survey (HDSA survey).*** Additionally, the HD community was invited to share their answers to the discussion questions asked during the meeting through an online portal hosted by HDSA. This portal was open until January 31, 2025. This report summarizes the comments from the meeting, the HDSA survey, and the online portal.

Scan the QR Codes for recordings of Sessions One and Two

Discussion questions, agenda and survey responses can be found in the Appendix (pg. 21)

SESSION 1 **SESSION 2**

Adult HD is a rare progressive neurological disease affecting more than 40,000 people in the United States. It is caused by an autosomal dominant mutation in the huntingtin gene. Individuals may begin to notice a decline in their mental health and cognitive abilities in their thirties. Motor skills decline as the disease progresses, with the emergence of involuntary movements (chorea) and the impairment of voluntary movements, which result in reduced manual dexterity, slurred speech, swallowing difficulties, problems with balance and falls. Most people with HD develop motor symptoms in their forties and fifties. There is currently no disease-modifying therapy for HD. Therapies available for people living with HD are limited to managing certain aspects of the symptoms. The phases of HD range from at-risk, pre-symptomatic, early, mid, and late.

In the research community, there has been an effort to harmonize the language describing the course of HD through the establishment of the HD Integrated Staging System (HD-ISS) which encompasses a biological definition of HD (based solely on the presence of the gene mutation) and Stages that recognize the progression of disease throughout a person's lifetime. In the HD-ISS there are four stages:

Stage 0: HD – presence of the expanded HD gene

Stage 1: Biomarker of disease development — detection of HD biology in laboratory tests such as the results from brain scans

Stage 2: Observation of HD features in motor skills and/or cognitive abilities

Stage 3: Functional change – difficulty doing, or the inability to do, routine activities independently

In the context of the HD-ISS the pre-symptomatic phase is referring to the time before clinical motor diagnosis in Stage 0, 1, and mid-Stage 2. And the early, mid, and late stages correspond to the time after clinical motor diagnosis in late Stage 2 and Stage 3.

While past clinical trials have focused on symptom management associated with adult clinically diagnosed HD, many of today's clinical trials focus on therapy development programs that intervene in HD at earlier phases. This meeting focused on experiences of people living with pre-symptomatic, early, and mid-stage HD (HD-ISS Stages 0 to mid HD-ISS Stage 3).

Meeting Participation by Stage

	Pre	Early	Mid	At Risk or Late	Don't Know, Prefer Not to Say	Care Partner	Total
In Person	17	10	20	7	—	—	**54***
Virtual	33	20	20	26	—	—	**92***
Portal Comments	33	20	20	26	—	—	**92**
HDSA Survey	119	192	168	239	115	212	**1,045**

** Care partner/family member included in the in-person virtual and online totals.*

Arik Johnson, Psy.D., HDSA Chief Mission Officer

OPENING REMARKS

In his opening statement, **Arik Johnson, Psy.D.,** Chief Mission Officer for HDSA, made a call to action, stating the time is now for the medical product development ecosystem to come together to speed innovation in the development of new therapies to treat HD. As research moves into finding disease-modifying therapies to slow the progression of the disease, research has moved to the earlier stages. As a result, clinical trials are shifting to enroll people in earlier stages. It is vital that we understand the varying treatment outcome preferences and benefit risk tolerance of people living with HD based on the stage of the disease they are living with.

Teresa Buracchio, M.D., Director of the Office of Neuroscience, Center for Drug Evaluation and Research at FDA, stated the agency shares the community's commitment to facilitate the development of safe and effective medical products for HD. She added that when the agency talks about medical product development, they mean the term broadly; beyond just drugs. It encompasses the identification, development and evaluation of potential therapies or devices that can help patients manage their condition. Dr. Buracchio emphasized that patients are experts in the lived experience of their disease. Further, patients are uniquely positioned to inform regulatory agencies and provide an understanding of the burden of disease and currently available treatment.

85% of HDSA survey respondents state they are aware of new therapies to treat HD

75% state they actively seek out information to stay current on the latest developments.

Key Themes

The meeting focused on the impact of living with HD, perspectives on treatment, preferred treatment outcomes, and perspectives on clinical trial participation. Several key themes emerged.

Impact of Living with HD
While insights from the EL-PFDD meeting, online comments, and the HDSA survey indicate that the impact of living with HD evolves as the disease progresses, several general themes emerged.

Diagnostic and Clinical Recognition Gaps
Individuals with pre-symptomatic HD often experience subtle cognitive, psychiatric, and emotional changes that do not meet clinical thresholds for diagnosis or treatment. Healthcare systems often dismiss these early symptoms, leading to delayed monitoring and unmet care needs.

Psychological Burden of Genetic Status
The knowledge of carrying the HD gene contributes to chronic anxiety, anticipatory grief, and emotional distress — even in the absence of overt symptoms. The uncertainty of symptom onset and progression creates persistent psychological strain.

Impact on Life Planning and Reproductive Decisions
Living with a known risk of HD significantly influences decisions related to education, careers, relationships, and family formation. Participants reported delaying or forgoing parenthood, and some pursue assisted reproductive technologies to prevent transmission of the gene.

Mental Health and Behavioral Complications
Depression, anxiety, suicidality, compulsive behaviors, and emotional dysregulation are prevalent in both pre-symptomatic and early and mid-stage HD. These mental health challenges are often exacerbated by a lack of clinical support for individuals in the pre-symptomatic stage and increasing disease burden among all stages.

Progressive Loss of Independence and Function
As HD progresses, individuals face increasing challenges in cognitive, motor, and daily functioning. These impairments disrupt employment, self-care, communication, and social participation, often resulting in reduced autonomy and increased caregiver burden.

PERSPECTIVES ON TREATMENT

Insights from the EL-PFDD meeting, online comments, and the HDSA survey indicate that perspectives on treatment evolve as HD progresses. Key themes include:

Urgent Need for Disease-Modifying Treatments
Participants across all stages of HD emphasized the lack of therapies that can alter the course of the disease. While some medications help manage symptoms, they do not slow progression. This absence of effective intervention leaves individuals and families feeling helpless, especially those living with pre-symptomatic HD who know symptoms are inevitable but have no options to prevent them.

Reliance on Lifestyle Approaches in the Absence of Medical Guidance
With no approved disease-modifying therapies individuals frequently turn to lifestyle changes, such as diet, exercise, supplements, and stress management. However, these efforts lack standardized, evidence-based guidelines, leading to confusion, inconsistency, and concerns about misinformation.

Access to Care Challenges
Participants described major hurdles in accessing HD-specialized care, including long-distance travel, limited provider networks, and insurance restrictions. Even when insured, many individuals struggle to obtain consistent, affordable medication or timely access to specialists, leading to treatment gaps that affect disease management.

Complex, Evolving Treatment Needs
As HD progresses, participants shared that treatment requires a constantly adjusted, multidisciplinary approach. Symptom management — especially for motor, cognitive, and psychiatric symptoms — relies on trial-and-error with medications, support therapies, and alternative treatments. Side effects, drug interactions, and evolving symptoms demand personalized, adaptable care.

PREFERRED TREATMENT OUTCOMES

Treatment priorities shift by disease stage. In early-stage HD, there is a focus on managing cognitive and psychiatric symptoms. As the disease progresses, priorities shift to addressing physical symptoms such as chorea, swallowing issues, and fall prevention. However, participants shared common themes among the stages.

Desired Outcomes That Focus on Daily Living, Not Just Survival
Rather than simply prolonging life, participants prefer treatments that support meaningful engagement in family life, relationships, and personal interests — emphasizing quality of life over duration.

Functional Independence and Communication Define Quality of Life
Participants value treatments that preserve the ability to work, drive, engage socially, and express themselves.

Clear Metrics Needed for Evaluating Treatment Efficacy
Suggested outcome measures include reduced falls and choking, validated cognitive tests, biomarker evidence of slowed progression, and preserved capacity for independent living and communication.

PERSPECTIVES ON CLINICAL TRIAL PARTICIPATION

Insights from the EL-PFDD meeting, online comments, and the HDSA survey indicate that perspectives on clinical trials can differ depending on the stage individuals live with. Regardless, several key themes emerged.

Eligibility Criteria and Timing Barriers
Participants frequently encounter exclusion from trials due to being in the pre-symptomatic stage, despite experiencing subtle neurodegenerative changes. The criteria often fail to align with the realities of disease progression, leading to frustration and urgency about missing a critical window for intervention. Likewise, those in the mid-stage have concerns that the disease is too advanced to be eligible.

Access and Logistical Challenges
Geographic distance to trial sites, travel limitations, and rigid participation protocols (e.g., strict scheduling, required follow-ups) create significant barriers for both patients and caregivers, particularly those managing the physical and logistical burdens of HD.

Communication Gaps and Enrollment Complexity
Trial information is often difficult to understand due to medical jargon, unclear eligibility requirements, and lack of a streamlined enrollment process. Automated recruitment tools depend on clinician engagement, which is inconsistent, creating further access issues.

Balancing Risk and Benefit
Willingness to assume risk varies across disease stages and individual circumstances. While some are hesitant due to potential side effects, others are willing to take significant risks for even modest benefits — especially as symptoms progress and quality of life declines.

Concern for Future Trial Eligibility
Many participants are hesitant to join current studies if doing so could disqualify them from future trials. Despite this concern, a substantial portion remains open to participation, reflecting a strategic and hopeful outlook toward emerging therapies.

Understanding the Natural History of Huntington's Disease

Victor Sung, M.D., Professor of Neurology, Division of Movement Disorders and Director, HDSA Center of Excellence at University of Alabama Birmingham, shared that although HD is classified as a rare disease, it is time for HD to receive the same visibility as other more well-known diseases. While the Rare Disease Advisor defines rare as a prevalence of 8.87 per 100,000, the US prevalence of HD was as high as 13.1 per 100,000 according to a 2017 Medicare study.[3] While that puts HD squarely in the realm of rare diseases, the prevalence is actually similar to that of ALS.

The HTT gene located on chromosome 4 encodes a protein called huntingtin. In HD, there is a mutation that is an expansion of the CAG trinucleotide repeat within the gene. Everyone has some number of these repeats, but in people with HD, the number is higher. A count of 40 or more CAG repeats is considered positive for HD.

Depending on the number of CAG repeats, the age of symptom onset in adult HD is between 30 and 50 years old. The natural clinical course varies from person to person, but it can span 15 to 30 years from the onset of symptoms to death. The cause of death is typically not the disease itself, but complications associated with it, such as pneumonia or falls. Pre-symptomatic is a stage defined as before overt symptoms start. The Shoulson and Fahn staging system groups symptomatic HD (HD-ISS Stage 3) into three stages: early, middle, and late. The early stage can be identified by the domains that focus on difficulties at work, leaving the workplace, needing help with financial affairs, but still functioning at home. During the middle stage, the individual can no longer manage household responsibilities and may need help with basic daily activities like bathing, dressing, feeding, and toileting. The late stage is defined here by the need for professional nursing care.

***3.** This study is referring to cases of clinical motor diagnosis rather than cases defined by the biological definition of the HD-ISS.*

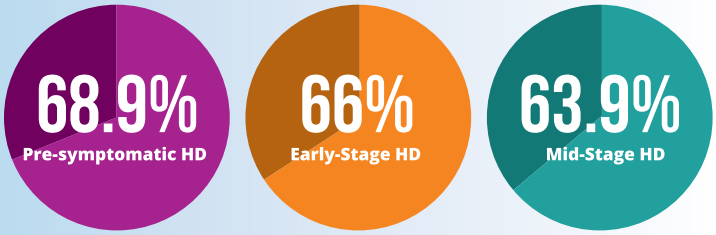
Victor Sung, M.D., Professor of Neurology, Division of Movement Disorders and Director, HDSA Center of Excellence at University of Alabama Birmingham

Session One:
Health Effects and Daily Impacts

The input from Session One focused on health effects and daily impacts of living with HD. While the comments and the HDSA survey results underscore the diversity in people's experiences living with HD, several key themes emerged:

- *The emotional toll of a positive test result*
- *Living with looming loss of abilities*
- *Planning for inevitable dependence*
- *Worries about the future of living with HD*

WORRIES ABOUT THE FUTURE LIVING WITH HD



SESSION ONE PANELISTS

A panel of four individuals, one living with pre-symptomatic HD, one with early-stage HD, one with mid-stage HD, and a family member brought these themes to life with their statements.

BRITTANY / ***Pre-symptomatic HD***

Brittany has tested positive for HD but is not yet exhibiting classic motor symptoms. She currently serves as a caregiver for her mother, who resides with Brittany and her husband. Her caregiving approach is informed by observing her mother care for a family member who had HD. Following her positive genetic test result, Brittany and her spouse opted not to pursue biological children due to the risk of transmitting the gene. She reported ongoing concerns about her future health and potential loss of abilities such as working, traveling, and engaging in hobbies including dancing and reading. Brittany indicated experiencing anticipatory grief related to expected functional decline. She also noted reduced optimism about future treatments following the discontinuation of a clinical research program for a disease-modifying therapy.

"I also have anxiety, which latches onto the uncertainty and knowledge I will someday develop symptoms. When will I develop symptoms? What symptoms will be most prominent? How long will I be able to work? How will my mind be impacted? My mood? My relationships?"
— Brittany

Pictured left and right are panelists from Session One.

DENISE / *Early-Stage HD*
Denise has early-stage HD and inherited the condition from her father. She has experienced cognitive decline, particularly in multi-tasking, concentration, and executive functioning. These impairments led to job loss. Denise's cognitive and psychiatric symptoms, including panic disorder, depression, and anxiety, are currently managed with medication. As her condition has progressed, Denise has experienced physical challenges including loss of balance and motor coordination. She reported recent injuries due to falls. Limitations in driving ability have emerged, with two accidents occurring in recent months. Driving remains a critical function in maintaining independence.

"Something as simple as walking my dog, which used to bring me joy, has become the most stressful part of my day due to balance issues." **— Denise**

LINDA / *Mid-Stage HD*
Linda was diagnosed with HD after presenting with involuntary movements. She has two siblings who also carry the gene. Linda described difficulty with decision-making and executive functioning, including trouble completing basic tasks such as grocery shopping. As the disease progressed, she experienced increasing limitations in physical mobility and coordination. Formerly active in sports and outdoor recreation, Linda now has difficulty using sports equipment and maintaining balance. She has begun practicing with a walker for mobility support. Speech difficulties have also emerged, including slurred speech, which affects interpersonal communication.

"I continue to travel, but it is becoming more of a challenge, as my gait has changed from being unnoticed, to stumbling more, falling more and not being confident in walking any length of distance by myself." **— Linda**

JEFF / *Caregiver*
Jeff is the primary caregiver for his wife, who is in the early stages of HD. He currently spends approximately 30% of his day assisting with her activities of daily living and managing challenges related to cognitive impairment, memory loss, and functional decline.

He reported having to provide continuous supervision and adjust to changes in her behavior, including mood swings and disorientation. He anticipates future increases in care needs and the possibility of transitioning his wife to long-term care, although he remains committed to providing care at home for as long as feasible.

"As her disease progresses, she will require ever increasing levels of assistance from me until we reach a point where I can no longer provide all the care that she requires. It will be a difficult day for both of us when we reach that point, because I want to ensure that she has only the highest quality of care and a loving, calm home life." **— Jeff**

Impact on Daily Life: Pre-symptomatic Huntington's Disease

The term **pre-symptomatic**[4] is often used for those who test positive for HD but do not yet exhibit classic, outwardly visible symptoms. Many participants expressed frustration with the clinical model that rigidly defines pre-symptomatic as an absence of physical symptoms and does not account for the psychological symptoms of living with a positive genetic test.

LIVING WITH AN UNCERTAIN FUTURE

Participants described long-term uncertainty related to symptom onset, disease progression, and life planning. Educational, career, and family decisions are often influenced by the anticipated future decline. Almost one quarter of HDSA survey respondents with pre-symptomatic HD report delaying or choosing not to pursue parenthood. Some individuals have opted for assisted reproductive technologies, such as in vitro fertilization with preimplantation genetic testing, to avoid passing on the gene.

"One of the biggest impacts HD has had on our life is planning for children. We had to undergo IVF, which was all paid out of pocket."

Subtle changes in cognitive and psychiatric functioning, although impactful, may not meet current diagnostic thresholds, leaving individuals in a state of diagnostic uncertainty. "There's a lot of uncertainty in this stage. The first time I went to my doctor he said come back in five years. People need more guidance, action and information. That would help the depression, the anxiety, the uncertainty."

Attempting to plan long-term is challenging. One participant asked, "How can you map out your career, finances, or family goals without knowing if you'll be independent and high-functioning in 5, 10, or 20 years?"

"Every time I stumble or am clumsy, I worry — my mind going straight to the HD. Every time I am forgetful, I worry it is the HD. Even though I know everyone without HD does this too at times."

Participants also reported concern about their potential future care needs and the impact on their families. These include the possibility of becoming dependent on spouses or children, and the psychosocial consequences of role changes within the household.

"We are trying to do as much as we can at this point in our life because retirement isn't guaranteed. We are traveling, we are keeping physically fit, we are trying to make sure we know as much as we can about the disease now so we can be prepared for the future."

PRE-SYMPTOMATIC DOES NOT MEAN "NO SYMPTOMS"

Although participants reported experiencing depression, anxiety, emotional dysregulation, and subtle cognitive changes, they indicated that these symptoms were often not considered sufficient by healthcare providers to warrant treatment or clinical monitoring. Some participants noted that this lack of recognition may contribute to ongoing psychological challenges associated with knowing they have inherited a genetic brain disorder. As one participant shared, "Everyone that has tested positive has symptoms. The fact that you know what your future's likely going to be is a symptom. And it's very difficult to deal with."

4. In the HD-ISS, the pre-symptomatic phase would refer to Stage 0 and Stage 1 of HD. The entrance to Stage 2 is rated on the presence of motor and clinical signs and symptoms as determined by exceeding thresholds on specific clinical outcome assessments as compared to an age-matched control population.

This is further complicated in individuals with CAG repeat lengths in the 36–39 range, who may or may not develop full symptoms due to reduced penetrance. One participant shared, "A lot of people don't realize it, but people in that range from 36 to 39, they can be symptomatic. And I am very much in that category of being symptomatic."

In the HDSA survey, 60% of respondents with pre-symptomatic HD reported they are not receiving care to address the condition. Participants shared that providers often advised them to return for evaluation in several years, potentially delaying care until after symptom onset. Participants expressed interest in receiving baseline evaluations and ongoing monitoring to detect subtle changes over time.

"You walk into a neurologist's office, and they don't see symptoms, there's no treatment, there's no conversation."

Comments from EL-PFDD and online portal participants:

LIVING WITH PRE-SYMPTOMATIC HUNTINGTON'S DISEASE

Good Day

- At this point, it's just ignoring completely what is down the line.
- Trying to stay in the moment instead of focusing on what HD holds.
- Living completely normal.

Bad Day

- Wondering if something that happened is due to HD or not.
- Struggling with memory issues and lashing out.
- Overthinking about the future and feeling anxious about it.

Living with Symptoms: Early and Mid-Stage Huntington's Disease

As HD progresses, individuals experience increasing impairments in mobility, communication, cognition, and swallowing function. Participants with **early-stage HD**[5] reported experiencing mild cognitive and psychiatric changes, which intensify over time and impact the ability to work, manage finances, and maintain independence. Observed behavioral changes include increased anxiety, depression, and irritability, as noted by family members.

In **mid-stage HD**[5], chorea — characterized by involuntary, jerky movements — becomes more prominent. Participants indicated that these movements interfere with daily tasks and increase the risk of injury from falls. Speech and swallowing difficulties also become more pronounced, with many individuals identifying deteriorating communication ability as a major concern.

PROFESSIONAL AND FINANCIAL CONCERNS

Executive function impairment that affects planning, organizing, and task execution were also reported. Over 70% of HDSA survey respondents in early and mid-stage HD note difficulties with memory and concentration, which impacted their ability to remain employed. One participant shared, "I have a very technical background, and my cognitive decline has made it difficult for me to maintain my role at my office."

Participants described that early symptoms disrupted professional and personal routines. Individuals from various professions, such as law, administration, editing, and music, reported that cognitive and motor impairments interfered with career responsibilities. As one participant shared, "When you're at the professional level of any profession, even the smallest decline in your abilities means you lose everything."

This loss of professional identity and financial strain was echoed in the HDSA survey with 51% of mid-stage and 40% of early-stage HDSA survey respondents reporting financial instability. As one meeting participant shared, "It is devastating to the psychology and the personality when you lose everything that you've worked for. We have a loving family, but your professional career is just gone."

"My HD caused me to stop working because I couldn't keep up with my job tasks, and I forgot how to perform parts of my job like losing my train of thought completely while presenting to senior executives and customers."

IMPACT ON DAILY LIFE

Participants reported that early and mid-stage HD significantly affects daily functioning and overall well-being. Tasks that were previously routine, such as baking, gardening, or playing an instrument, became difficult or unmanageable. One participant shared, "Even going into a grocery store, where I could do it before is very difficult to do now."

Communication challenges due to speech and language impairments were frequently noted as contributing to reduced social interaction and increased isolation. The HDSA survey indicates that 41% of respondents with early-stage HD and 67% with mid-stage HD no longer participate in previously enjoyed social activities. One participant shared that their spouse's symptoms prevented him from having a job, from maintaining friendships, from living independently and leading a normal life.

"We just don't necessarily get included in some of the activities because we can't. It's hard. It's difficult. I think a lot of it is we're not necessarily included because we're not doing certain things. We're not having a dinner to discuss buying tickets or because we're not going to tailgating or football games."

Participants reported progressive difficulty with self-care activities, such as grooming and meal preparation, due to lack of mobility. This loss often leads to assistance from care partners. The inability to eat or swallow properly can lead to significant weight loss, malnutrition, and a diminished quality of life. The HDSA survey data show that 75% of mid-stage HD respondents experience stumbling and clumsiness, 70% report chorea, and 56% experience difficulty swallowing.

5. *In the HD-ISS, clinical motor diagnosis typically occurs in the later part of HD-ISS Stage 2 or in HD-ISS Stage 3.*

"I can remember all those times falling in the shower, out of the shower, falling on the street and being afraid because people would look at me and say, are you drunk? Are you high?"

IMPACT ON BEHAVIORAL AND MENTAL HEALTH

Participants shared that loss of independence can lead to depression. Nearly 50% of early and mid-stage survey respondents reported symptoms of depression. One participant shared that his wife's uncle "started showing symptoms and then went and committed suicide within a couple of months because he knew what was coming on, what was going to happen."

"We do think about suicide. Our family members think about suicide. Our family members worry about us committing suicide."

Fixations, obsessions and compulsive behaviors were also reported. One participant shared, "If I get fixated on a task and I am not able to immediately resolve it, it completely disrupts the rest of my day or week." Participants reported that these behaviors can also include repetitive viewing of media, compulsive spending, and ritualistic patterns. Of the HDSA survey respondents, 40% living with early-stage HD and 50% living with mid-stage HD report experiencing obsessions and compulsions.

Participants reported challenges in intimate and interpersonal relationships, often related to changes in cognitive, mental health and physical functioning. As one family member reported, "The biggest challenge in his early stage was the behavioral... not being able to manage the anxiety. He experienced emotional outbursts at work, at home."

Comments from EL-PFDD and online portal participants:

LIVING WITH EARLY AND MID-STAGE HUNTINGTON'S DISEASE

Good Day

- A good day starts with a good night's sleep and being able to complete tasks that we start.
- Waking up in the morning, getting up out of the bed, taking a shower and participating in family activities.
- We just look at ourselves and say, it's okay to not be perfect.

Bad Day

- Falling, vomiting, throwing things.
- Depression takes over.
  I don't want to see anybody.
  I don't want to talk to anybody.
- Feeling like I want to die.

Session Two: Perspectives On Treatment

Participants shared frustration around knowing that HD symptoms are inevitable, and that individuals living with HD and their families are powerless to stop its progression. Further, despite best efforts to maintain a healthy lifestyle through diet, exercise, and supplements, there is no proven way to prevent or delay the onset of symptoms. While there are medications to treat some of the mental health and movement disorder symptoms, there are no disease-modifying therapies that stop the progression. Four panelists opened this session.

SESSION TWO PANELISTS

BRANDON / ***Pre-symptomatic HD***
He described his efforts to research treatment options following a positive test result, while not yet experiencing symptoms. He shared this observation about treatment options: "There are none. There is nothing. I'm on my own. My family is on our own. And each Huntington's disease family is on their own." As a result, he shared that he and his family are relying on non-clinical strategies such as diet and supplements. Brandon also discussed the impact of HD on his mother, who has since died, noting that while some medications helped manage her symptoms, they had trade-offs, including reduced awareness.

"The need for treatment still exists, stronger than ever, and the lack of options leaves individuals like my mom, like me, helpless. We are forced to sit idle, knowing this disease is progressing silently within us, without any way to intervene." **— Brandon**

Pictured above are panelists from Session Two.

RYAN / ***Early-Stage HD***
He participated in a clinical trial from 2019 to 2021, which involved 13 spinal taps. He shared that he experienced some benefits from the trial but is currently ineligible for the ongoing study. He is now enrolled in a cognitive trial that has had a significant positive impact, but he is concerned it may be discontinued.

"Without further progress or access to potential therapies, the consequences for patients like me are severe. I am urging decision-makers to consider innovative approaches and expedite development and approval pathways for Huntington's disease treatments." **— Ryan**

NATHAN / ***Mid-Stage HD***
His statement was read by his wife, Heather, due to speech challenges. He was diagnosed at age 18 and shared a family history involving HD. His statement reflected his experience of daily care needs, his outlook on treatment development, and the intergenerational impact of HD on his family. Nathan emphasized his ongoing engagement with HD care and research despite functional decline. He shared that, "if my symptoms never got any worse than what they are at this moment my family and I would be happy."

"I still have a quality of life. I still have a family that loves me and wants me to be with them. If I and my family are willing to go to whatever lengths it takes to help me and others like me, then you should too. If I haven't given up, then why should you?" **— Nathan**

JEREMY / ***Caregiver***
He shared his and his wife's experiences post-diagnosis, including their travels around the country to HD clinical experts, engagement with support groups, and advocacy efforts. Jeremy described their attempts to access clinical trials and his wife's commitment to wellness practices. He noted challenges with trial eligibility due to her current pre-symptomatic clinical status and described the frustration they feel around that current reality.

"Why are we waiting for the disease to manifest before we start trying to make strides toward a cure or delaying the disease onset?" **— Jeremy**

Perspectives on Treatment: Pre-symptomatic Huntington's Disease

Participants living with pre-symptomatic HD reported a lack of formal, evidence-based guidelines on approaches to potentially delay symptom onset. While general wellness practices are commonly promoted, participants shared concerns that there is no consensus-driven protocol endorsed by the medical community. They also shared concerns that eligibility for clinical trials is limited.

LIFESTYLE AND HEALTH CARE GAPS

Without approved treatments, those living with pre-symptomatic HD commonly shared that they explore various lifestyle adjustments and dietary regimens in hopes of delaying the onset of symptoms. Participants reported a range of nutritional strategies, including plant-based diets, food eliminations, and the use of various supplements. Strategies participants shared include:

- "I Exercise every day, eat as healthy as possible."
- "I stick to a vegan (sometimes vegetarian) diet and try to incorporate exercise."
- "My favorite exercise has been fitness kickboxing, which is as much for mental health as it is physical."

HDSA survey respondents share that nearly 30% use vitamins as part of symptom management. In addition to diet changes, many adopt a holistic approach through regular exercise, stress-reduction techniques like yoga and meditation, and prioritize quality sleep.

The approaches are as diverse as the individuals themselves, driven by a combination of anecdotal evidence and scientific theories. Over 60% of the HDSA survey respondents living with pre-symptomatic HD report they get their information from an HDSA Center of Excellence, 55% from the HDSA website and 38% from family and friends.

Participants described difficulty maintaining consistency with lifestyle regimens due to work and family responsibilities, financial limitations, or limited access to care. One participant noted, "The major downside is that it's hard to be consistent with it when you want to live your life to the fullest."

"A lot of people don't have the financial means to afford a healthy lifestyle. Supplements cost money. Not everybody has an HD doctor that's accessible to them. It's important to identify the people that don't have access to trusted providers to feel safe."

Even among those with insurance, specialist care may not be geographically accessible. The lack of nearby trusted providers who fully understand the condition is challenging. 60% of pre-symptomatic respondents to the HDSA survey report they are not receiving any care to treat HD, yet almost 45% state they take an SSRI.

Participants indicated a strong interest in receiving formal guidance on evidence-based approaches for the pre-symptomatic stage. Even without a guarantee of symptom onset delay, such recommendations would offer a structured strategy for managing the condition.

"There isn't really a recommended regimen. It would be very helpful to have a set of guidance, an official stamp of approval that something actually does work. It doesn't have to guarantee that it works. But whether it's supplements or lifestyle choices, because there's a lot of information and misinformation on the internet. Everyone's doing their own research. And in this phase of the disease, it would be very helpful to have what we think could help the damage we know is being done, even though we don't have symptoms yet."

Perspectives on Treatment: Early and Mid-Stage Huntington's Disease

Individuals living with early and mid-stage HD require a comprehensive, multidisciplinary approach to treatment. HD specialized care teams include neurologists, psychiatrists and other healthcare professionals who collaborate to develop integrated care plans tailored to the evolving nature of HD symptoms. Effective treatment includes careful evaluation of pharmacologic options and medication management, often requiring precise dosing, side effect monitoring, and ongoing adjustments based on clinical response.

ACCESSING SPECIALTY CARE

Locating healthcare providers with expertise in HD remains a significant challenge. Participants reported traveling long distances to reach HDSA Centers of Excellence or other medical institutions with knowledgeable staff. In some cases, this travel extends to out-of-state facilities, creating logistical and financial burdens. Telehealth was reported as an alternative; however, individuals in rural areas cited limited access to reliable internet and appropriate technology as barriers to participation. One family shared, "It would have been easier to drive into the city than to participate in a telehealth appointment."

"She can't travel anywhere further than however long she can go without using the restroom."

MANAGING SYMPTOMS

As HD progresses, common symptoms include cognitive impairments (e.g., difficulty with memory, focus, and information processing) and emotional regulation challenges. Participants described addressing these symptoms through a combination of pharmacological interventions, therapeutic modalities, and lifestyle adaptations. Examples include enrolling in educational courses, engaging in cognitive activities, and incorporating structured daily routines. One participant reported she took the advice of her doctor and enrolled in college courses, taking one class at a time. She is now working towards a master's degree.

"There's not one medication that's going to suit everybody. It's going to change constantly with what we need. And each person is different. Since I was diagnosed seven years ago, mine has probably changed anywhere up to ten times."

Pharmacologic interventions for symptom management include antidepressants, anxiolytics, and cognitive aids for dementia. Treatment plans often involve trial-and-error to identify effective drug combinations with tolerable side effect profiles. Chorea, a characteristic motor symptom of HD, is commonly treated with VMAT2 inhibitors such as tetrabenazine, deutetrabenazine, and valbenazine. These medications may reduce involuntary

MEDICATIONS USED TO TREAT HD
2024 HDSA HD Symptoms and Treatment Impact Survey

MEDICATION	PRE-SYMPTOMATIC	EARLY-STAGE	MID-STAGE
Benzodiazepines	8.9%	23.1%	26.3%
SSRI	44.6%	43.8%	35.1%
SNRI	7.1%	19.8%	31.6%
Mood Stabilizers	5.4%	16.5%	14%
Neuroleptics	7.1%	19.8%	28.1%
Sleep Aids	17.9%	24%	0.7%
Cognitive Aids for Dementia	0%	1.7%	.9%
VMAT2	0%	13.2%	28.9%

movements but can also produce adverse effects requiring dosage adjustments.

Pain and sensory discomfort related to clothing was also noted as a persistent, difficult-to-treat symptom. While various strategies were attempted, participants reported limited success in alleviating these issues. One participant shared, "Socks were super uncomfortable — tags on clothing, sitting. Anything that you can imagine hurt." One participant shared the challenges they had finding a solution for a family member's pain. "He had pain all the time, and I don't recall all of the different things that were tried, but it seemed like nothing ever worked. No matter what treatments we tried, nothing ever eased his discomfort."

Some individuals use complementary and alternative therapies, including cannabis-based treatments, to manage focus, anxiety, and behavioral symptoms as described by this participant, "I take medical cannabis pills. I also do mindfulness, yoga and meditation."

ADJUSTING TO DISEASE PROGRESSION

As HD progresses, participants shared that their symptoms change and evolve, presenting new challenges that require constant adjustments to treatment plans. What may have initially helped with anxiety can become ineffective as depression or mobility issues take precedence.

This continuous symptom evolution necessitates a flexible and responsive approach to care. Treatments that once provided relief for certain symptoms may lose their efficacy or cause intolerable side effects as the disease advances. Medications that help manage chorea movements can lead to cognitive impairments or other adverse effects over time.

Over 55% of the early and mid-stage respondents to the HDSA survey share that they make medication adjustments while working with their providers to minimize symptoms. One-quarter of early-stage HDSA survey respondents share that they participate in physical, speech or occupational therapy. This number rises to 50% for the mid-stage cohort.

"I work with my doctors to take my knowledge and theirs and say, let's play around a little bit. Let's try this and try this much. I've always believed that it's harder to take away medications than it is to start at a baseline and then go up."

ACCESSING AFFORDABLE CARE

Participants reported that access to affordable treatment and consistent medication availability remains a substantial barrier. Insurance limitations were cited as a primary concern, particularly when specific medications or providers were not included in coverage networks. Some individuals experienced disruptions in care due to changes in insurance plans or provider networks. One participant shared this impact, "Our Insurance changed with a job loss, then we had to change centers and start all over again."

Medication access is not just about affordability; it's also about reliable distribution channels. Many participants shared that they experience severe anxiety when their medications are not delivered on time through mail-order pharmacies. Limited availability of HD-specific medications at local pharmacies was also reported. This highlights the critical nature of uninterrupted access, as even brief lapses can significantly impact symptom management and quality of life.

"I had meltdowns because my medication was not on time and down to the last pill. I was terrified because no hospital carries this medication."

Overall, the participants expressed frustration and dissatisfaction in current treatments available to treat early and mid-stage HD. One participant summed it best by stating, "Ultimately everything gets worse because we're not treating the underlying cause of HD."

Preferred Treatment Outcomes

Participants shared that treatment priorities shift depending on disease stage. In the pre-symptomatic stage, participants emphasized treatments to address subtle changes they are noticing around mental health and cognition: "Treatments that will help with controlling the cognitive and emotional effects and delaying onset as long as possible."

In the early-stage, participants emphasized the importance of addressing cognitive and psychiatric symptoms, such as impaired thinking, memory difficulties, anxiety, and depression. These symptoms impair key functional capacities that affect the ability to work, engage in daily life, and maintain independence. Participants emphasized the need for treatments that improve cognitive difficulties including those that support time management and task completion. "I want to reduce cognitive decline and protect judgment."

Participants also shared that at this stage, loss of small motor skills became evident as shared by this participant, "I wish, more than anything, to regain my fine motor skills. I want to be able to sew again, doing hand-stitching so that I can work on finishing an heirloom quilt that has been passed down to me. I also want to be able to put Legos together with my family. This used to be one of our Christmas morning traditions, but due to my frustration with not being able to pick up small pieces, we had to give this up, much to my son's disappointment."

As HD progresses, participants shared that they place greater emphasis on managing physical symptoms that increasingly interfere with basic functioning. These include swallowing difficulties, nutritional concerns, and involuntary movements. At mid-stage HD, participants shared that treatments that support safe eating, reduce choking risk, and minimize falls were important to them. "What I'd like to give my wife back is her dignity and the ability to go to the bathroom, and her activities of daily living that she's losing right now."

This evolving preference for treatment outcomes is echoed by the HDSA survey respondents. The number one preferred symptom reduction for people living with pre-symptomatic and early-stage HD is difficulty concentrating. For people living with mid-stage HD, chorea is ranked as number one.

DEFINING COGNITIVE DECLINE

Participants provided a wide range of descriptions for cognitive decline. Commonly reported domains included feeling present, being able to multi-task, being able to communicate, being able to drive, advocating for oneself, maintaining good judgement, making appropriate decisions, making sound financial decisions. Definitions varied but generally aligned with the capacity to participate in daily life and maintain independence. Detailed examples include:

- ***"It's that cognitive side and the executive dysfunction and how much it really affects your life... I multi-tasked in many ways and I can't do it anymore."***
- ***"Being able to just think more clearly, not lose my train of thought, just remember things and have those memories continue."***
- ***"Being able to think through the next three things in a recipe but then cut the things in the recipe."***

Many participants shared they are seeking to recapture or improve communication, as described by this participant, "The loss of my best friend and intimacy and all those good things that you have between a husband and a wife. I'd like to be able to stop it right now and allow my wife to continue to communicate to us her feelings and her needs. We lost that. It's heartbreaking."

MEASURING TREATMENT EFFICACY

Participants shared that measures useful in evaluating whether treatments are effective are those that address key symptoms and support maintaining quality of life. Participants shared the following as potential indicators of treatment efficacy:

- Reduction in falls and choking episodes
- Standardized cognitive assessments such as the Stroop Color Word Test
- Preservation of functional independence, including the ability to drive, work, perform routine self-care tasks, and participate in physical and social activities
- Biomarkers that indicate slowed disease progression

Improving or not losing the ability to express oneself is another marker of treatment success. As one caregiver stated, "Without communication, the cognition is only halfway. It seems like I've looked at my wife now for almost a year and there's no communication."

EVOLVING TREATMENT TO LIVING BETTER WITH HD

Participants expressed a preference for treatments that go beyond merely extending their lifespan. As one participant stated, "This is not about what I want. It's when I want it."

There was consistent interest in treatments that enable a shift from a view of HD as terminal to a view of it as a condition that can be managed over time. Comparisons were made to chronic disease models in other conditions, such as HIV, where treatment allows for sustained quality of life and prolonged functional ability.

Participants emphasized the need for therapies that delay symptom progression and support continued engagement in daily life, as described by this participant, "I want to be able to continue to participate with my family. I need symptom management until there's something better, delaying some of those cognitive types of things so that I can still participate in life."

Participants shared they want to avoid the apathy and withdrawal that often accompanies the later stages, where they are physically present but unable to truly connect or engage with their surroundings. "We're not really sure we want to be in some of these really hard stages long, because they're so impactful to our families," remarked one participant.

Perspectives on Clinical Trial Participation

Participants identified several barriers to clinical trial participation. Stringent eligibility criteria often exclude individuals who do not yet exhibit sufficient symptoms, despite underlying neurodegeneration. Logistical challenges, including travel distance to trial sites and rigid participation requirements, further limit access. Communication issues, such as unclear trial information and technical language, contribute to difficulties in understanding and enrolling.

ELIGIBILITY CRITERIA CHALLENGES

The years of neurodegeneration that occur prior to the onset of overt symptoms may represent a critical window for effective intervention. However, prevailing clinical trial designs often exclude individuals in the pre-symptomatic phase of HD due to challenges in measuring clinical endpoints. Stringent inclusion criteria, while necessary to ensure scientific validity, frequently limit participation among individuals in the pre-symptomatic stage.

Pre-symptomatic participants noted being ineligible for trials because they were considered "too healthy," with insufficient symptoms to meet eligibility thresholds despite evidence of underlying neurodegenerative changes. They shared concerns that their fading health is deemed "not bad enough" while fearing that the window to participate in clinical trials will permanently close.

One participant's comment captured this sentiment, "I can tell by how fast I can do certain things and puzzles I can and can't do anymore. But we can't get into those trials because we aren't 'bad enough' yet."

"I didn't get tested to sit around and do nothing about it. I got tested to actively get into a trial right away, and I pray to God every day that that will happen."

Among those living with early and mid-stage HD there is an urgency felt by many, a race against time to find interventions that can stop the progression before it is too late. Many feel time is rapidly slipping away for interventions to be maximally effective as expressed by this participant, "The reality for us is death. We don't have other options. That really needs to be stressed because that's how serious it is."

Families are willing to go to extraordinary lengths for the chance to participate. "I will go bankrupt. I will lose everything if it means helping my husband and helping my kids," one family member declared.

ACCESS BARRIERS

For many individuals and families affected by HD the biggest obstacle to participating in clinical trials revolves around travel and mobility issues. Participants described situations where trials are too far away or require levels of travel that are unfeasible given their circumstances.

One participant shared, "Their treating clinic did not offer a particular trial of interest. Our only option was to travel to a distant site, potentially in another state." Another participant shared that extended travel is not a realistic possibility for their spouse given where they are in the disease. Another echoed this challenge, noting, "While resources like trial finders can identify study locations, getting to those sites and meeting participation requirements like follow-up visits is extremely difficult for many."

Even when trials are relatively local, strict enrollment protocols can exclude willing participants. Rigid schedules for check-ins or assessments, like having to be available for phone calls from researchers at the same time each day for weeks, prove too burdensome for some families to manage amidst the realities of living with HD while juggling other life and work responsibilities.

"It was too cumbersome. We didn't even go through the process. We would have had to be at home at the same time each day to receive a phone call from the investigator. We had to do that, I think, for 3 or 4 weeks, and that was just too much burden on our part."

COMMUNICATION AND ENROLLMENT CHALLENGES

Participants indicated a lack of clarity and transparency in trial descriptions and eligibility criteria. The use of technical language and the absence of a direct enrollment pathway through platforms like clinicaltrials.gov were cited as significant obstacles. Some observational studies, such as Enroll-HD, use automated systems to identify potential participants, but these rely on clinician engagement, which is not consistent across all settings.

"If you want people to participate in trials, they have to be able to understand why they should, what's the benefit to them. And it's not going to happen if we're using words like biomarker. What does that mean to the average person on the street? You're going to miss a huge group of people."

WEIGHING RISKS VS. POTENTIAL BENEFITS

The level of acceptable risk varies from person to person based on their stage of disease and personal values around quality of life. In the pre-symptomatic stage, people with HD may be more cautious, as one participant explained, "Until I'm closer to symptomatic, I wouldn't do a trial with the hope of just delaying progression due to unknown adverse reactions." However, their perspective often shifts as the disease robs them of abilities. "When I become symptomatic, I'd be willing to try just about anything."

Many are willing to take on significant personal risks for even modest potential gains. "If it can buy me a year to get to the next trial, I'll do it," one participant said. For some, delaying onset or progression of symptoms by months can mean extra time to live more normally.

The prospect of further compromising their limited capabilities is a concern. Some participants expressed trepidation about invasive procedures like spinal taps or brain surgeries, not only due to the inherent risks, but also the potential for discomfort or setbacks in their condition.

PROTECTING FUTURE TRIAL ELIGIBILITY

For many participants, the driving force behind participating in clinical trials is the hope of accessing future, potentially more effective treatments. As a result, there is significant concern about joining trials that can inadvertently disqualify them from participating in subsequent, more promising studies as shared by this participant, "[only] the types of trials that would prevent trying a different trial later on as medical science discovery comes up with more effective trials."

According to HDSA survey data, the top concerns related to trial participation were future ineligibility and potential side effects. Despite this, approximately 50% of all survey respondents report they would still consider enrolling, while 11% state they would not participate if it jeopardized future eligibility.

"If it's not providing significant benefit or a very short period of time and I can't participate in research in the future, then I don't know that I would do it. But if it can buy me a year to get me to the thing that's coming up and I can get into that research next."

Conclusion

Individuals living with HD and their families experience a wide range of challenges that affect daily functioning and quality of life. These include cognitive impairments that impact work, family responsibilities, relationships, driving, and task management, as well as physical symptoms such as loss of balance, involuntary movements, and swallowing difficulties that interfere with basic activities. The variety and progression of symptoms highlight the need for treatments that address multiple dimensions of the disease.

While symptom management priorities may vary depending on disease stage, cognitive function was consistently identified as a key concern. Treatments that preserve cognitive abilities and communication skills may support continued autonomy and social engagement.

Those affected do not merely seek treatments that extend their lifespan, but ones that allow them to truly live with HD. They seek therapies that can preserve their independence, enable continued participation in activities and relationships, and maintain a sense of normalcy for as long as possible. Ultimately, the goal is to improve their daily lived experiences and overall quality of life.

Development of therapies that address the complex and evolving symptoms of HD remains a priority for the HD community. Continued research is necessary to advance treatment options that reflect the full spectrum of patient needs.

Huntington's Disease Society of America

VOICE OF THE PATIENT REPORT

Living with Huntington's Disease

Appendix

APPENDIX A

Agenda

WEDNESDAY, NOVEMBER 13, 2024		
TIME	**TOPIC**	**PRESENTER**
9:30 - 9:40	Welcome	Arik Johnson, PsyD, HDSA Chief Mission Officer
9:40 - 9:45	Opening Remarks	Dr. Teresa Buracchio, Director, Office of Neuroscience, CDER, FDA
9:45 - 10:00	Clinical Overview of HD	Dr. Victor Sung, Professor of Neurology, Division of Movement Disorders and Director, University of Alabama HDSA Center of Excellence
10:00 - 10:25	Panel 1: Health Effects and Daily Impacts	One representative from each group: pre-symptomatic stage, early-stage, mid-stage and family member
10:25 - 11:05	Large Group Facilitated Discussion: Pre-symptomatic Health Effects and Daily Impacts	Community Participants *(Inperson and Virtual)*
11:05 - 11:45	Large Group Facilitated Discussion: Early-stage Health Effects and Daily Impacts	Community Participants *(Inperson and Virtual)*
11:45 - 12:30	Lunch	All
12:30 - 1:10	Large Group Facilitated Discussion: Mid-stage Health Effects and Daily Impacts	Community Participants *(Inperson and Virtual)*
1:10 - 1:35	Panel 2: Current Approaches to Treatment	One representative from each group: pre-symptomatic stage, early-stage, mid-stage and family member
1:35 - 2:35	Large Group Facilitated Discussion: Pre-symptomatic Current Approaches to Treatment	Community Participants *(Inperson and Virtual)*
2:35 - 2:50	Break	All
2:50 - 3:50	Large Group Facilitated Discussion: Early-stage Current Approaches to Treatment	Community Participants *(Inperson and Virtual)*
3:50 - 4:50	Large Group Facilitated Discussion: Mid-stage Current Approaches to Treatment	Community Participants *(Inperson and Virtual)*4:50 -
5:00	Closing Remarks	Arik Johnson, PsyD, HDSA Chief Mission Officer

APPENDIX B

Meeting Discussion Questions

TOPIC 1: HEALTH EFFECTS AND DAILY IMPACTS

1. Of all the symptoms that you experience because of your condition, which 1-3 symptoms have the most significant impact on your life? Examples may include depression, difficulty concentrating, bowel/digestive issues, stumbling/clumsiness, etc.
2. Are there specific activities that are important to you but that you cannot do at all or as fully as you would like because of your condition? Examples of activities may include participation in work, family responsibilities, sports, or social activities, intimacy with a spouse or partner, daily hygiene, etc.
3. As it relates to your condition, what does a good day look like? What does a bad day look like?
4. How has your condition and its symptoms changed over time?
5. Would you define your condition today as being well managed?
6. What worries you most about your condition?

TOPIC 2: CURRENT APPROACHES TO TREATMENT

1. What are you currently doing to help treat HD symptoms? Examples may include prescription medicines, over-the-counter products, and other therapies including non-drug therapies such as diet modification.
2. How has your treatment regimen changed over time, and why?
3. How well does your current treatment regimen treat the most significant symptoms of HD that you experience? For example, how well do your treatments improve your ability to do specific activities?
4. How well have these treatments worked for you as your condition has changed over time?
5. What are the most significant downsides to your current treatments, and how do they affect your daily life? Examples of downsides may include going to the hospital or clinic for treatment, time devoted to treatment, restrictions on driving, etc.
6. Short of a complete cure, what specific things are most important to you around delaying the progression of HD?
7. What do you consider the most beneficial functional improvements if you could regain what you have lost or anticipate losing?
8. Do you have any concerns about participating in a clinical trial?

APPENDIX C

HDSA HD Symptoms and Treatment Impact Survey Results

METHODOLOGY

The Huntington Disease Society of America (HDSA) wanted to understand the impact living with HD symptoms and the impact treatment has on people with adult-onset pre-symptomatic, early and mid-stage Huntington's disease. Further HDSA wanted to understand the perspective of future treatments and participation in clinical trials of this group. In June 2024 HDSA convened a Family Council to assist with the development of the survey. The Council provided input and helped shape the questions and response options.

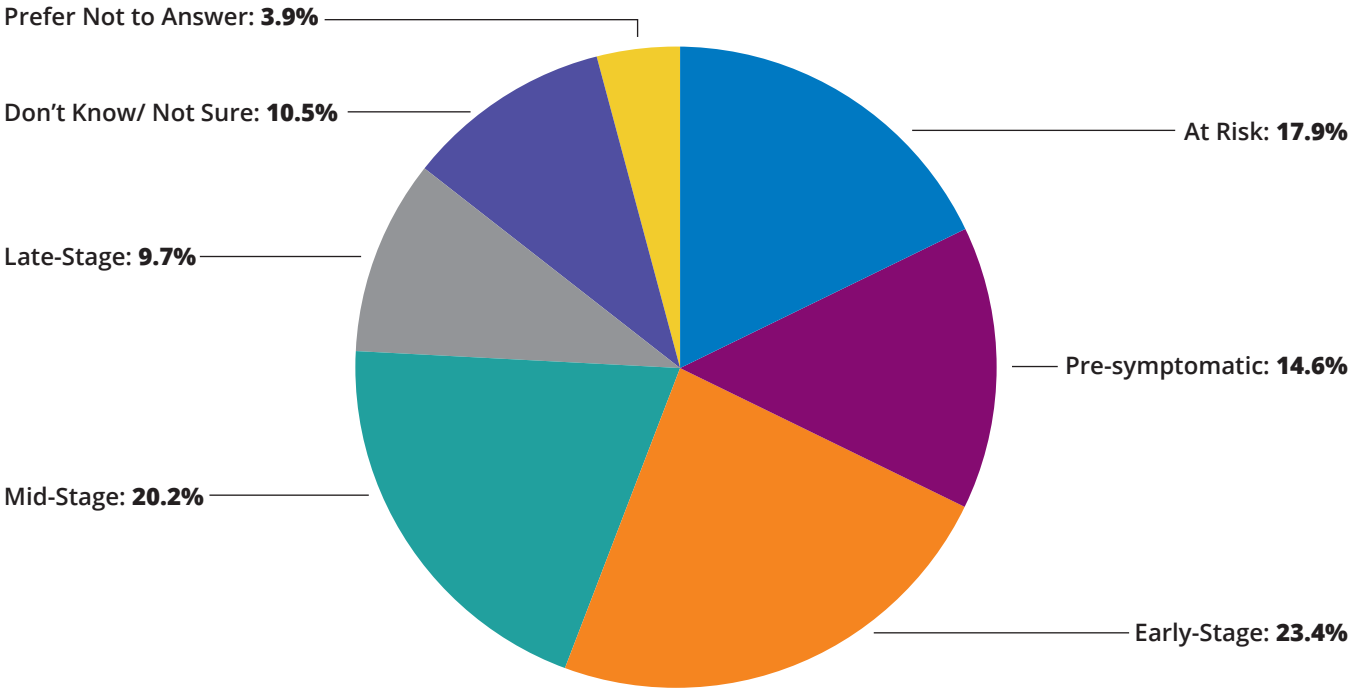
The survey was promoted through the HDSA communication channels and social media, HDSA support groups and HDSA chapters from July 2024 through October 2024. It was also shared with other HD patient advocacy organization to distribute.

Individuals were disqualified from the survey if they had no relationship to HD. 1,095 qualified to take the survey. Respondents were not required to answer each question, therefore the number of responses to each question varies.

While the survey was open to all individuals with a relationship to HD, results displayed in this document beyond question 2 represent those living with pre-symptomatic, early and mid-stage adult on-set HD.

DEMOGRAPHICS

1. What stage of HD do you live with?
(Care partners and family members were instructed to answer the question based on the status of the family member living with HD.)



2. What is your age?

	Pre-symptomatic	Early-Stage	Mid-Stage
18-24	4.3%	1.1%.	7%
25-34	19.0%	4.0%	0.7%
35-44	37.1%	20.9%	14.2%
45-54	19.8%	28.2%	22.3%
55-64	12.1%	26.6%	31.1%
65+	7.8%	19.2%	31.1%

3. What gender do you identify with?

	Pre-symptomatic	Early-Stage	Mid-Stage
Male	27.4%	25.7%	36.0%
Female	71.8%	74.3%	64.0%
Non-binary/Other	0.9%	0%	0%

4. What is your ethnicity?

	Pre-symptomatic	Early-Stage	Mid-Stage
White/Caucasian	85.5%	90.0%	92.7%
Hispanic or Latin	4.3%	3.9%	2.0%
American Indian or Alaska Native	3.4%	1.1%	0.7%
Asian/Pacific Islander	0.9%	2.2%	0%
Black or African American	0%	1.1%	1.3%
Multiple Ethnicity	1.7%	1.6%	2.0%
Prefer not to answer	0.9%	0%	1.3%
Other	1.7%	0%	0%

APPENDIX C

5. Where do you live?

	Pre-symptomatic	Early-Stage	Mid-Stage
United States	89.7%	93.3%	94.5%
Europe	3.4%	0.6%	1.3%
Canada	1.7%	1.1%	2.0%
United Kingdom	0.9%	1.7%	1.3%
Australia	0.9%	2.2%	0.7%
Other	0.34%	1.1%	0.7%

6. What is your marital status?

	Pre-symptomatic	Early-Stage	Mid-Stage
Married	60.7%	61.7%	78.8%
Widowed	4.3%	5.6%	6.2**%**
Divorced	7.7%	13.9%	9.6%
Separated	0.9%	2.2%	0.7%
Single	21.4%	12.8%	4.8%
Prefer Not to Say/Other	5.1%	4.0%	2.7%

7. What is your employment or academic enrollment status? *(Select all that apply)*

	Pre-symptomatic	Early-Stage	Mid-Stage
Full-Time Employment	67.5%	34.3%	26.0%
Part-Time Employment	11.1%	9.4%	4.0%
Full-Time Student	4.3%	0.6%	0.7%
Part-Time Student	2.6%	1.1%	0%
Retired	9.4%	30.4%	38.0%
Unemployed	6.0%	7.2%	4.0%
Unable to Work	3.4%	13.3%	20.7%
SSDI	0.9%	17.7%	21.0%

DIAGNOSIS

1. Do you have a diagnosis of HD?

	Pre-symptomatic	Early-Stage	Mid-Stage
Yes	68.4%	84.0%	64.7%
No	31.6%	16.0%	5.3%%

2. If yes, how long have you been diagnosed?

	Pre-symptomatic	Early-Stage	Mid-Stage
Less Than 1 Year	16.3%	13.2%	1.0%
1 Year	2.5%	8.6%	4.0%
1-3 Years	18.8%	27.2%	14.0%
3-6 Years	23.8%	13.2%	25.0%
6-9 Years	13.8%	15.9%	27.0%
10+ Years	25.0%	21.9%	29.0%

3. Was your diagnosis made on the basis of, or confirmed by a genetic test?

	Pre-symptomatic	Early-Stage	Mid-Stage
Yes	98.8%	95.9%	98.0%
No	1.3%	4.1%	2.0%

4. Where do you receive your care for the treatment of HD?

	Pre-symptomatic	Early-Stage	Mid-Stage
I am pre-symptomatic. Do not receive care for HD.	60.3%	—	—
Primary Care Physician	5.2%	21.1%	16.3%
Medical Specialty Clinic *(Such as Neurology)*	10.3%	40.0%	37.3%
HDSA Center of Excellence	31.0%	53.9%	52.3%
I have HD but am not receiving care for HD.	5.2%	6.0%	5.9%

APPENDIX C

SYMPTOMS

1. What symptoms of HD have you experienced in the last 30 days? *(Select all that apply.)*

	Pre-symptomatic	Early-Stage	Mid-Stage
Not experiencing symptoms	55.0%	1.8%	0.7%
Difficulty concentrating	2.1%	72.9%	74.3%
Memory lapses	18.3%	66.9%	73.0%
Depression	29.4%	47.0%	50.7%
Anxiety	36.7%	71.1%	59.5%
Anger/Irritability	19.3%	50.0%	59.5%
Obsessions/Compulsions	11.9%	40.45	50.0%
Personality changes	7.3%	33.7%	43.2%
Difficulty with sexual functioning	4.6%	22.9%	29.7%
Bowel/digestive changes	7.3%	25.3%	36.5%
Stumbling and clumsiness	14.7%	58.4%	75.0%
Chorea	7.3%	52.4%	70.3%
Problems swallowing	3.7%	27.7%	56.15%
Problems speaking and breathing	4.6%	27.1%	43.9%
Difficulty moving and/or with mobility	2.8%	24.1%	56.1%
Other	3.7%	12.7%	14.9%

2. Please select the four symptoms that have the most impact on your life today.

	Pre-symptomatic	Early-Stage	Mid-Stage
Not experiencing symptoms	58.9%	0.6%	1.2%
Difficulty concentrating	27.1%	51.8%	35.9%
Memory lapses	16.8%	41.5%	27.5%
Depression	23.4%	33.5%	25.4%
Anxiety	28.0%	52.4%	39.4%
Anger/Irritability	20.6%	33.5%	25.4%
Obsessions/Compulsions	6.5%	22.0%	26.8%
Personality changes	0.9%	18.9%	17.6%
Difficulty with sexual functioning	2.8%	6.1%	4.9%
Bowel/digestive changes	3.7%	9.1%	9.9%
Stumbling and clumsiness	7.5%	34.1%	43.0%
Chorea	2.8%	31.1%	38.0%
Problems swallowing	3.7%	11.0%	28.2%
Problems speaking and breathing	3.7%	15.9%	28.2%
Difficulty moving and/or with mobility	2.8%	11.6%	26.1%

3. How has living with the HD symptoms impacted your life? *(Select all that apply.)*

	Pre-symptomatic	Early-Stage	Mid-Stage
My life has not been impacted by HD.	23.6%	2.5%	0.7%
Educational goals have been delayed or not pursued.	10.4%	16.7%	10.4%
Unable to do work I have done previously.	14.2%	58.6%	74.3%
Unable to perform work I have received training or advanced education for.	8.5%	45.1%	52.8%
Unable to explore new employment, training, or academic opportunities.	14.2%	45.1%	41.7%
Professional growth has not been achieved.	8.5%	35.2 %	25.7%
Financial instability.	12.3%	40.7%	51.4%
Delay or choose not to get married or enter into a life commitment.	13.2%	14.8%	12.5%
Delay or choose not to start a family.	23.6%	19.1%	13.9%
Family responsibilities are more difficult.	17.0%	46.9%	51.4%
Strained family, intimate or personal relationships.	26.4%	41.4%	53.5%
No longer engage in social activities I used to enjoy.	12.3%	41.4%	67.4%
No longer participate in physical activities I used to enjoy.	10.4%	40.7%	63.9%
Loss of independence.	5.7%	27.8%	63.2%
No longer able to drive.	1.9%	15.4%	54.9%
Caring for a family member with HD is more difficult.	16.0%	14.2%	29.9%
Worries about the future of living with HD.	68.9%	66.0%	63.9%

APPENDIX C

4. Please select the four activities that have been most impacted due to living with HD.

	Pre-symptomatic	Early-Stage	Mid-Stage
My life has not been impacted by HD.	27.2%	1.3%	0.7%
Educational goals have been delayed or not pursued.	7.8%	7.5%	1.5%
Unable to do work I have done previously.	8.7%	37.1%	40.4%
Unable to perform work I have received training or advanced education for.	2.9%	25.2%	26.5%
Unable to explore new employment, training, or academic opportunities.	10.7%	22.0%	11.8%
Professional growth has not been achieved.	5.8%	11.9%	6.6%
Financial instability.	12.6%	32.7%	39.7%
Delay or choose not to get married or enter into a life commitment.	10.7%	8.25	4.4%
Delay or choose not to start a family.	24.3%	8.8%	4.4%
Family responsibilities are more difficult.	13.6%	26.4%	20.6%
Strained family, intimate or personal relationships.	18.4%	29.6%	33.8%
No longer engage in social activities I used to enjoy.	9.7%	30.8%	30.9%
No longer participate in physical activities I used to enjoy.	8.7%	21.4%	30.1%
Loss of independence.	5.8%	18.2%	43.2%
No longer able to drive.	1.0%	7.5%	38.2%
Caring for a family member with HD is more difficult.	12.6%	8.2%	15.4%
Worries about the future of living with HD.	61.2%	50.3%	30.1%

PERSPECTIVES ON TREATMENT

1. What medications for HD do you take? ***(Select all that apply.)***

	Pre-symptomatic	Early-Stage	Mid-Stage
Benzodiazepines for anxiety: Xanax (alprazolam), Valium (diazepam), Klonopin (clonazepam), Ativan (lorazepam), etc.	8.9%	23.1%	26.3%
SSRI antidepressants: Prozac (fluoxetine), Zoloft (sertraline), Lexapro (escitalopram), Celexa (citalopram), Paxil (paroxetine)	44.6%	43.8%	35.1%
SNRIs/other antidepressants: Khedezla/Pristiq (desvenlafaxine), Cymbalta / Drizalma / Irenka (duloxetine), Fetzima (levomilnacipran), Savella (milnacipran), Effexor (venlafaxine), Remeron (mirtazapine), Wellbutrin (buproprion)	7.1%	19.8%	31.6%
Mood stabilizers: Depakote (valproate), Trileptal (oxcarbazepine), lithium, Tegretol (carbamazepine), Neurontin (gabapentin), Lamictal (lamotrigine)	5.4%	16.5%	14.0%
Neuroleptics/antipsychotics: Risperdal (risperidone), Zyprexa (olanzapine), Abilify (aripiprazole), Seroquel (quetiapine), Prolixin (fluphenazine) Haldol (haloperidol)	7.1%	19.8%	28.1%
Sleep aids for insomnia: trazodone, Restoril (temazepam), Ambien (zolpidem), Lunesta (eszopiclone), Unisom (doxylamine), melatonin	17.9%	24.0%	30.7%
Cognitive aids for dementia: Aricept (donepezil), Razadyne (galantamine), Exelon (rivastigmine), Namenda (memantine)	0%	1.7%	0.9%
VMAT2 inhibitors for chorea: Xenazine (tetrabenazine), Austedo (deutetrabenazine), INGREZZA (valbenazine)	0%	13.2%	8.9%
Other: Adderall, Ritalin, *(majority are med categories listed above, or vitamins which are not meds)*	10.0%	20.0%	28.0%
None:	15.0%	4.0%	0.5%

APPENDIX C

2. What have you tried to minimize your HD symptoms? *(Select all that apply.)*

	Pre-symptomatic	Early-Stage	Mid-Stage
I am not experiencing HD symptoms.	54.5%	0.8%	2.0%
Medication prescribed by my medical provider without changes	10.2%	36.7%	33.3%
Medication adjustment or a new medication while working with my medical provider	10.2%	53.9%	55.3%
Medication adjustment on my own	2.3%	14.8%	4.0%
Vitamins and/or nutritional supplements	28.4%	53.1%	42.1%
Support group meeting	18.2%	30.5%	25.4%
Talk therapy	20.5%	38.3%	24.6%
Physical, occupational or speech therapy	4.5%	25.8%	50.0%
Mind-body therapies such as meditation, guided imagery, relaxation, hypnosis, biofeedback, prayer, expressive therapies (dance, art and music) and breathwork	18.2%	27.3%	16.7%
Cannabis (marijuana) - inhaled or ingested	8.0%	21.9%	12.3%
Psychedelics, such as psilocybin	3.4%	6.3%	1.8%
Body-based therapies, such as osteopathic manipulation, chiropractic, massage and reflexology	12.5%	15.6%	15.8%
Energy therapies such as reiki, or electromagnetic fields therapies such as pulsed, magnetic and alternating-current or direct-current field	3.4%	9.4%	2.6%
Diet adjustments	28.4%	30.5%	31.6%
Physical exercise	36.4%	51.6%	44.7%
Clinical trial participation	15.9%	25.8%	24.6%
I don't do anything to try and minimize my symptoms	6.8%	3.1%	7.0%

3. What resources do you use to find information to help you manage symptoms? ***(Select all that apply.)***

	Pre-symptomatic	Early-Stage	Mid-Stage
Clinical care team	37.5%	58.6%	57.8%
HDSA Center of Excellence	62.5%	61.7%	63.8%
HDSA website	55.7%	57.8%	54.3%
Pharmaceutical websites	12.5%	16.4%	7.8%
Support group	34.1%	27.3%	28.4%
HD peers	33.0%	23.4%	25.9%
Family and friends	38.6%	52.3%	47.4%
Health information websites	39.8%	35.9%	27.6%
I don't try to find any information	5.7%	4.7%	4.3%

4. There are currently no therapies that cure or stop the progression of HD symptoms. Reflecting on the list below, If you could have a reduction in symptoms which four would make the most positive change in your life?

	Pre-symptomatic	Early-Stage	Mid-Stage
My life has not been impacted by HD	38.2%	2.4%	0.8%
Difficulty concentrating	27.0%	52.0%	30.8%
Memory lapses	18.0%	44.0%	33.3%
Depression	24.7%	28.0%	23.3%
Anxiety	24.7%	48.0%	35.8%
Anger/Irritability	22.5%	27.2%	28.3%
Obsessions/Compulsions	9.0%	15.2%	25.8%
Personality changes	19.1%	29.6%	17.5%
Difficulty with sexual functioning	1.1%	5.6%	5.0%
Bowel/digestive changes	0%	5.6%	9.2%
Stumbling and clumsiness	6.7%	34.4%	41.7%
Chorea	23.6%	40.0%	45.0%
Problems swallowing	12.4%	16.8%	30.8%
Problems speaking and breathing	18.0%	14.4%	29.2%
Difficulty moving and/or with mobility	15.7%	22.4%	30.0%

5. If treatment could improve your ability to participate in activities that are important to you, which ones would be the most important? *(Please select four.)*

	Pre-symptomatic	Early-Stage	Mid-Stage
My life has not been impacted by HD	30.7%	0%	1.6%
Pursue educational goals	6.8%	4.8%	1.6%
Be able to do work I did previously	12.5%	34.4%	40.2%
Be able to do work I have received training or advanced education for	9.1%	18.4%	21.3%
Be able to explore new employment, training or academic opportunities	4.5%	15.2%	9.0%
Achieve professional growth	15.9%	9.6%	4.1%
Achieve financial stability	18.2%	24.0%	27.9%
Pursue marriage or life commitment	10.2%	15.2%	5.7%
Start a family	13.6%	6.4%	2.5%
Maintain family responsibilities	28.4%	32.8%	40.0%
Enjoy positive relationships	25.0%	43.2%	27.0%
Engage in social activities I enjoy	18.2%	36.8%	41.8%
Participate in physical activities I enjoy	22.7%	8.4%	34.8%
Live with greater independence	14.8%	24.8%	44.3%
Be able to drive	3.4%	18.4%	35.2%
Care for a family member with HD	9.1%	4.8%	2.5%
Less worry about the future of living with HD	46.6%	38.4%	35.2%

FUTURE TREATMENTS PERSPECTIVE

1. Many therapies to treat a disease have a limited time span of benefits and taking the therapy again after that time span has expired does not provide any additional benefit. Reflecting on the stage of HD you live with now, if the benefits of a therapy to slow or stop HD progression were expected to last for a limited time span without future benefit, what would be the minimal acceptable time period for you?

	Pre-symptomatic	Early-Stage	Mid-Stage
Less than 6 months	7.2%	4.4%	9.6%
6 months	6.0%	3.5%	2.9%
1 year	12.0%	16.7%	18.3%
18 months	3.6%	6.1%	7.7%
3 years	15.7%	15.8%	12.5%
5 year	18.1%	22.8%	24.0%
7 years	6.0%	3.5%	1.0%
10+ year	31.3%	27.2%	24.0%

2. Many therapies to treat a disease have a limited time span of benefits, but taking the therapy again provides those same benefits for the same time period of time. In this scenario how often would you be willing to take the therapy?

	Pre-symptomatic	Early-Stage	Mid-Stage
Every day	62.7%	48.2%	52.4%
Every week	3.6%	8.8%	4.9%
Every two weeks	1.2%	0%	0%
Once a month	12.0%	12.3%	13.6%
Every three months	9.6%	5.3%	7.8%
Every six months	3.6%	2.6%	4.9%
Once a year	2.4%	14.0%	5.8%
Every couple of years	4.8%	7.0%	5.8%
I would not be willing to repeat the treatment	0%	1.8%	4.9

3. Therapies often come with significant side effects. Reflecting on the stage of HD you live with now, please rank 1-8 (with one being the highest) the acceptable time frame of HD symptom-free benefit that is acceptable in light of potential side effects.

	Pre-symptomatic	Early-Stage	Mid-Stage
I gain any amount of HD symptom-free life.	3	2	2
I gain an additional 1-5 years of HD symptom-free life.	2	3	4
I gain more than 10 years of HD symptom-free life.	1	1	1
My HD symptoms are unlikely to stop, but the progression might slow.	6	6	5
My HD symptoms stop progressing for any amount of time before resuming progression.	7	7	7
My HD symptoms stop progressing for 1-5 years.	5	5	6
My HD symptoms stop progressing for more than 10 years.	4	4	3
I won't accept any risk of getting side effects.	8	8	8

4. Clinical research often occurs in stages. Therapies often provide limited symptom improvements at first with increasing improvements over many years or decades as new therapies become available. Given this timeline what are the four most important symptoms you would like to see new therapies address now?

	Pre-symptomatic	Early-Stage	Mid-Stage
Difficulty concentrating	29.3%	44.0%	36.1%
Memory lapses	34.1%	43.1%	29.6%
Depression	20.7%	25.0%	19.4%
Anxiety	13.4%	30.2%	25.0%
Anger/Irritability	30.5%	24.1%	20.4%
Obsessions/Compulsions	9.8%	12.1%	20.4%
Personality changes	47.6%	31.0%	24.1%
Difficulty with sexual functioning	1.2%	2.6%	3.7%
Bowel/digestive changes	2.4%	5.2%	4.6%
Stumbling and clumsiness	12.2%	33.6%	42.6%
Chorea	57.3%	48.3%	52.8%
Problems swallowing	32.9%	26.7%	34.3%
Problems speaking and breathing	45.1%	21.6%	33.3%
Difficulty moving and/or with mobility	42.7%	34.5%	32.4%

APPENDIX C

PERSPECTIVES ON CLINICAL TRIALS

1. Today there are no FDA approved therapies that cure or slow the progression of HD. However, there are medical products being tested in clinical trials that have the potential to provide disease-modifying benefits, including gene therapies. Please rate your awareness of new therapies being developed to treat HD.

	Pre-symptomatic	Early-Stage	Mid-Stage
Aware	53.7%	55.3%	46.5%
Somewhat aware	39.0%	35.9%	38.6%
Not aware	7.3%	8.7%	14.9%

2. Do you actively seek out information to stay current on the latest developments in new therapies to treat HD?

	Pre-symptomatic	Early-Stage	Mid-Stage
Yes	88.2%	80.7%	71.7%
No	11.8%	19.3%	28.3%

3. What might motivate you to consider participating in a clinical trial? *(Select all that apply)*

	Pre-symptomatic	Early-Stage	Mid-Stage
To help researchers learn more about HD and its treatment	88.9%	80.2%	70.1%
Help other people who are diagnosed with HD.	86.4%	71.7%	65.4%
Get access to a treatment being studied for HD that I couldn't get another way.	77.8%	72.6%	62.6%
Get better care for HD than I could get on my own.	61.7%	62.3%	54.2%
Knowing that my participation will help future generations of our families.	90.1%	73.6%	72.9%
Symptoms and effects of HD were so bad that I have no other options and could no longer work, study, or take part in everyday activities.	23.5%	28.3%	29.9%

4. It is not uncommon that a person can only participate in one clinical trial for a disease over their lifetime, especially if that trial is for gene therapy. If participating in one clinical trial or an experimental therapy meant that you could not participate in future clinical trials, what actions would you take?

	Pre-symptomatic	Early-Stage	Mid-Stage
I would not enroll in the trial.	7.4%	14.3%	10.0%
I would participate in the trial in hopes that it would be effective.	63.0%	50.5%	45.7%
I would participate in hopes that science would advance to allow for the possibility of being eligible or another new treatment in the future.	59.3%	45.7%	47.6%
I would participate because it is important to me to be on the cutting edge of science and help others in the community.	37.0%	37.1%	24.8%

5. What concerns would you have about participating in a clinical trial? ***(Select all that apply.)***

	Pre-symptomatic	Early-Stage	Mid-Stage
Taking time and energy away from work or school.	38.3%	22.9%	4.0%
Taking time and energy away from caring for a loved one with HD.	6.2%	8.6%	6.9%
Taking time and energy away from parenting responsibilities.	19.8%	16.2%	7.9%
Making me ineligible for future trials.	69.1%	51.4%	38.6%
Causing some harm or adverse effects to me.	56.8%	61.9%	63.4%
Creating uncertainty about my future health care and/or making it harder for my medical team to treat me in the future.	29.6%	30.5%	36.6%
The clinical trial does not succeed.	45.7%	45.4%	36.6%
Expenses associated with participating.	33.3%	31.4%	40.6%

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