OBJECTIVES: Huntington’s disease (HD) is a rare neurodegenerative disease leading to impaired mobility and poor quality of life (QoL) for patients as well as caregivers. This study, conducted in US as a part of an international survey, investigated a disease-specific QoL instrument, the HD QoL Battery for Carers (HDQoL-C). METHODS: The shortened version of the HDQoL-C comprised two components: one assessing QoL with life (3 items) and another assessing QoL with PD (17 items). Caregivers were asked to answer socio-demographic questions and complete the short version of the (HDQoL-C), a previously validated questionnaire. Item scores were summed to a total score (ranging from 0 to 20). Internal consistency and test-retest reliability were assessed. Validity was determined by comparing the QoL instrument against the CNS-LS.

RESULTS: The sample comprised of 361 family carers from US with 76% female, 16% single and 51% of average age. The majority of the caregivers represented the main caregivers of the HD patients with 73% of them lived with the HD patient. There were 2 items out of 20 with potential floor effects and 3 items with ceiling effects. Cronbach’s alpha coefficients ranged from 0.68 to 0.90 in the whole sample, indicating high internal consistency. Analyses of the component of the HDQoL-C dealing with the feelings (ranging from 0 to 10) demonstrated good internal consistency and congruent validity when compared to the original English version.

PND4 SEIZURE SEVERITY AMONG SUBJECTS WITH REFRACTORY PARTIAL-ONSET SEIZURES: ANALYSIS OF THE SEIZURE SEVERITY QUESTIONNAIRE IN A PHASE III TRIAL OF ESILCARBAZEPINE ACETATE

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OBJECTIVES: To examine seizure severity across treatment arms among clinical trial subjects with refractory partial-onset seizures (POS) who participated in a phase III clinical trial of eslicarbazepine acetate, a novel once-daily anticonvulsant recently approved for the adjunctive treatment of POS in adults.

METHODS: The Seizure Severity Questionnaire (SSQ), a validated instrument developed to evaluate the severity and bothersomeness of specific seizure characteristics, was administered. The SSQ total score (TS) and domain scores of frequency and helpfulness of warning signs before seizures (BS), severity and bothersomeness of ictal movement and altered consciousness during seizures (DS), cognitive, emotional, and physical aspects of postictal recovery after seizures (AS), and overall severity and bother (SB) were calculated at baseline and at the end of maintenance therapy (12-week duration) from the pre-protocol population. ANCOVA models, adjusted for baseline scores, estimated least square mean (LSM) differences between arms at the end of therapy. RESULTS: Among 547 subjects, average age: 38 ± 6.3; 50.8% female, 50.8% female, 70.4% (385) had TS results at baseline and at end-of-therapy. Among subjects receiving 1200 mg ESL, the TS LSM was significantly lower compared to placebo (2.80 versus 5.67, p = 0.001); the LSMs were also significantly lower for DS (3.29 versus 3.96, p = 0.001), but not for BS. Among subjects treated with 800 mg ESL, the LSM differences vs. baseline were 2.85 (p = 0.001) for BS, 3.96 (p = 0.001) for DS and 3.70 (p = 0.001) for AS. Among subjects treated with 800 mg ESL who were scored positive for TBI, there was no statistically significant difference. LSM differences were also significantly lower for DS (3.29 versus 3.96, p = 0.001), but not for BS. Among subjects treated with 800 mg ESL, the LSM differences vs. baseline were 2.85 (p = 0.001) for BS, 3.96 (p = 0.001) for DS and 3.70 (p = 0.001) for AS. Among subjects treated with 800 mg ESL, the LSM differences vs. baseline were 2.85 (p = 0.001) for BS, 3.96 (p = 0.001) for DS and 3.70 (p = 0.001) for AS.

CONCLUSIONS: In this post-hoc analysis of a phase III trial, ESL-treated subjects had statistically-significantly lower TS scores at the end of therapy compared to placebo. ESL-treated subjects had statistically-significantly lower DS scores at the end of therapy compared to placebo. ESL-treated subjects had statistically-significantly lower DS scores at the end of therapy compared to placebo. ESL-treated subjects had statistically-significantly lower DS scores at the end of therapy compared to placebo. ESL-treated subjects had statistically-significantly lower DS scores at the end of therapy compared to placebo.

PND45 SCREENING FOR PBA SYMPTOMS USING A SINGLE QUESTION VERSUS A 7 QUESTION MEASURE AND ASSESSMENT OF THE ASSOCIATION OF PBA SYMPTOMS WITH HRQOL BURDEN

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OBJECTIVES: PBA, characterized by uncontrollable episodes of crying and/or laughing, is a common symptom reported in adults with Cystic Fibrosis. Previous studies have reported a burden related to PBA and its impact on quality of life (QoL) in Cystic Fibrosis. However, the exact prevalence and impact of PBA on quality of life in Cystic Fibrosis is not known.

METHODS: De-identified medical visit transcriptions were analyzed to evaluate the burden associated with PBA in adults with Cystic Fibrosis. PRO topics observed in patient-provider conversations were captured and categorized (PQ, general symptoms, symptom-related PROs).

RESULTS: To describe the frequency and nature of patient-reported outcome (PRO) conversations between physicians and patients with Cystic Fibrosis. METHODS: A random sample of de-identified patients with Cystic Fibrosis in the United States was selected from a large de-identified database of medical office visit transcriptions. Transcriptions were based on physician dictated voice recordings detailing every individual patient encounter/visit. De-identified medical visit transcriptions were analyzed to evaluate the burden associated with PBA reported by Cystic Fibrosis patients and whether this burden was related to patient reported outcome (PRO). PRO topics observed in patient-provider conversations were captured and categorized (PQ, general symptoms, symptom-related PROs).

CONCLUSIONS: PBA is a symptom-related PRO that is commonly reported by adults with Cystic Fibrosis. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03). This finding is consistent with previous research demonstrating a relationship between disease severity and QoL. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03). This finding is consistent with previous research demonstrating a relationship between disease severity and QoL. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03). This finding is consistent with previous research demonstrating a relationship between disease severity and QoL. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03). This finding is consistent with previous research demonstrating a relationship between disease severity and QoL. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03). This finding is consistent with previous research demonstrating a relationship between disease severity and QoL. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03). This finding is consistent with previous research demonstrating a relationship between disease severity and QoL. The burden associated with PBA was related to symptom-related PROs, as a function of disease severity and QoL. PBA was more commonly reported in patients with greater severity of disease (r = 0.19, p = 0.03).