standing. Internal validity was tested, assessing internal consistency, correlation matrix using item/dimension correlation, factorial structure and differential item functioning. External validation was performed versus motor symptoms, behavioral symptoms, and the well-established QoL scale EuroQol. 5D. RESULTS: The preliminary analysis supported the validity of the H-Qol-l. Face validity appeared satisfactory (Missing data = 4%). as for the original instrument, a ceiling effect was observed in the patient sample. The H-Qol showed an acceptable reliability (Cronbach’s alpha > 0.85 for each dimension). The factor analysis explained 77% of the total variance and split the items in 3 factors in the same way as the original version. There was no differential item functioning neither between countries nor gender. The factor analysis demonstrated correlation between the clinical motor score and the motor functioning dimension was 0.89, between EQ-5D score and H-Qol-l total score, 0.71 and between the clinical depression/seriousness and the psychological dimension of H-Qol-l, 0.63. CONCLUSIONS: Test–retest and sensitivity to change remain to be performed, but current data support the validity of the H-Qol-l.

**PND40**

THE HUNTINGTON CLINICAL SELF-REPORTED INSTRUMENT (H-CSRI): VALIDATION IN GERMANY, POLAND AND USA

Clay ET1, Maird M2, Tourni M3, Tedoff J1, Squintet F1, De Nicola L4, Verny C5, Cohen J6

1Creatic Research, Paris, France, 2Creatic-Creativ, Lieu des Berg-C LHIS, TUNIS, Tunisia, 3University Claude Bernard Lyon1, Lyon, France, 4Neurosearch, Ballerup, Denmark, 5Neurogenetics and Rare Disease Centre, Pozzi, Italy, 6Centre national de référence des maladies neurogénétiques, Angers, France, 7Tufts University Center for the Study of Drug Development, Boston, MA, USA

OBJECTIVES: The H-CSRI is the first clinimetric patient assessed scale for patients with Huntington’s disease (HD). It was originally developed and validated for France and Italy. Such an instrument offers the advantage of allowing a remote follow-up and to get information on the development of motor, functional and behavioral disorders of HD patients perceived by the patient himself. The objective of this study is to adapt and cross-culturally validate the H-CSRI for Germany, Poland and USA. METHODS: The original questionnaire included three subscales assessed by 6 Likert-type items (motor, functional, and emotional dimensions), 7 Yes/No questions and the ability (13 Likert-type items in 4 dimensions). The instrument was translated forwards and backwards by native speakers. It was then reviewed and adjusted by local clinicians and tested for face validity. A total of 734 French, 50 Polish and 41 German HD patients filled in the H-CSRI questionnaire. Classical test theory and item response theory were used to assess its clinimetric properties. Cross-cultural validation was assessed by differential item functioning analysis. RESULTS: Among 235 patients, item response rates ranged from 86% to 93%. None of the items appeared satisfactory; as for the original instrument, there was a floor effect on items related to psychiatric disorder in the behavioral dimension. The H-CSRI showed an acceptable reliability (Cronbach’s alpha > 0.80). Factor analyses demonstrated a satisfactory construct validity for the motor dimensions with 76% of explained variance and for the behavioral dimensions with 74% of the explained variance. The differential item functioning analyses showed no item bias between the three countries and between genders. CONCLUSIONS: These data support the cross-cultural validity of the H-CSRI to assess the health status for patients with Huntington’s disease and integrate the patient perspective for Germany, Poland and USA.

**PND48**

DEVELOPMENT OF A BURDEN QUESTIONNAIRE: FAMILY BURDEN OF ICHTHYOSIS IN INFANTS

Bodemmer C1, Dufresne H2, Tzib C2

1Hospital Breker, Paris, France, 2FSSA, Bouloupe Billancourt, France

OBJECTIVES: Ichthyoses form a group of ailments for which the main part of treatment aims to reduce hyperkeratosis and to control sensory, articular and psychological complications. In infants, dermatologists do not restrict their treatment to the pathology. The concept of suffering could be structured around five components: feeling of pain, daily life, family and personal relationships, work and psychological impact. Ninety-six pre-sampled families and 133 questionnaires were answered. They were measured for at and below level pain in patients with traumatic SCI between the C3 and T10 level. A subgroup of items was assessed for constant pain. The item analysis revealed that pain was related to light disturbance and temperature-evoked pain. Scale reliability was 0.76 below and 0.80 at SCI level. Exploratory correlations with other standard diagnostic tools were moderate. Descriptor clustering disclosed 5 main groups of pain types covering most of the items used frequently in other instruments (DN4 or NPSI). Pain at and below SCI level is considered in specific subscales enabling a more specific exploration of the properties of the EuroDoMed are good and support the use of this new instrument to explore neuropathic pain in patients with SCI, although an effort should be made to shorten it without losing precision.

**PND50**

PREFERENCES FOR THE PREDICTIVE GENETIC TEST FOR ALZHEIMER’S DISEASE IN THE UNITED STATES

Huang MY1, Perri M2

1University of Georgia, Athens, GA, USA

OBJECTIVES: To assess public preferences for the predictive genetic test for Alzheimer’s disease in the United States. METHODS: A rating conjoint analysis was conducted using an anonymous online survey distributed by Qualtrics® to a general population panel in April 2011 in the United States. The study design included three attributes: Accuracy, Treatment Availability, and Anonymity. A total of 12 scenarios were used to elicit people’s preference by adopting an 11-point scale. The respondents also stated their highest willingness-to-pay (WTTP) for each scenario by answering the open-ended questions. RESULTS: A total of 295 responses were collected over four days. The results showed the most important attribute for the aggregate model was Accuracy, contributing 64.7% to the preference rating. Treatment Availability and Anonymity contributed 20.72% and 15.49% to the preference rating, respectively. The most preferred scenario was the test with a 100% chance of being correct, a cue for AD is available and the test result is anonymous. The median WTP for the highest-ranking scenario (Accuracy 100%, the test result is anonymous) was $100 (mean WTP was $276). The median WTP for the lowest-ranking scenario (Accuracy 40%, no cue but drugs for symptom relief, not anonymous) was zero (mean WTP was $36). Four groups were identified using cluster analysis revealing different patterns and preferences among the three attributes. CONCLUSIONS: The results of this study highlight the attributes consumer find important when making the decision to obtain an AD genetic test. These results should be of interests to policy makers, genetic test developers and health care providers.

**PND51**

THE RELATIONSHIP BETWEEN PATIENT-REPORTED HEALTH-RELATED QUALITY OF LIFE AND DISABILITY STATUS AMONG PATIENTS WITH MULTIPLE SCLEROSIS

Khalid KM1, Globe D1, Armstrong E2, Maloney D3, Coyne K4

1Allergan, LLC, Irvine, CA, USA, 2University of Arizona, Tucson, AZ, USA, 3University of Arizona, Tucson, AZ, USA, 4United Biotech Corporation, Bethesda, MD, USA

OBJECTIVES: Previous research suggests that the Short Form 36 (SF-36) may capture some of the broad effects of MS that are not reflected in the Kurtzke Expanded Disability Status Scale (EDSS). Our study was designed to explore the relationship between an EDSS-correlated self-reported disability measure, the Patient Determined Disease Steps (PDDS), and SF-36 health domain scores. METHODS: A cross-sectional sample of multi-visiting MS specialty centers were recruited through web-based patient advocacy organizations. Participants responded to questions pertaining to demographics, disease history, productivity, urinary symptoms, and HRQoL. Disability status was measured using the PDDS, an 8-point scale ranging from “normal” to “bedridden,” and SF-36 was measured using the SF-36 version 2, a 36-item questionnaire comprised of 8 health domain subscales and 2 summary scores normalized for direct comparison to the US general population. Spearman rank correlation coefficients were calculated to assess the relationship between SF-36 domain scores and PDDS scores. RESULTS: Among the sample of 1052 participants who completed the survey, 19% were men and the mean age was 48 years. All 8 SF-36 subscales were significantly

**PND52**

INITIAL PSYCHOMETRIC PROPERTIES OF THE EURODOLMED QUESTIONNAIRE: A NEW INSTRUMENT TO MEASURE NEUROPATHIC PAIN IN PATIENTS WITH SPINAL CORD INJURY (SCI) BASED ON PAIN INTENSITY, PAIN INTERFERENCE AND PAIN DESCRIPTORS

Taylor JS1, Ruiz MA2, Soler MD3, Bouhassira D4, Poole H5, Jauregui ML6, EuroDolMed SC7, Tinetti NB8

1Hospital Nacional de Parapléjicos, Toledo, Spain, 2Universidad Autonoma de Madrid, Spain, 3Hospital de Neurorehabilitación Instituto Guttmann, Badalona, Barcelona, Spain, 4Hospital de Neurorehabilitació Institut Paral · s, Barcelona, Spain, 5Hospital Cruces, Barakaldo, Bizkaia, Spain, 6Hospital Nacional de Parapléjicos, Toledo, Toledo, Spain, 7Aarhus University Hospital, Århus C, Århus, Denmark

OBJECTIVES: To develop a new instrument measuring neuropathic pain at and below the level of spinal cord injury (SCI) based on pain intensity, pain interference and pain descriptors. METHODS: An expert panel composed of pain specialists, physiologists, rehabilitation doctors, neurologists, psychologists and methodologists created the items and to supervise the questionnaire construction. There were two following Classic Test Theory assumptions. A total of 12 Likert items, 2 multi-choice items, 7 dichotomous indicators and 23 pain descriptors were proposed. They were measured for at and below level pain in patients with traumatic SCI between the C3 and T10 level. A subgroup of items was assessed for constant pain. Factor analysis for constant pain was related to light disturbance and temperature-evoked pain. Scale reliability was 0.76 below and 0.80 at SCI level. Exploratory correlations with other standard diagnostic tools were moderate. Descriptor clustering disclosed 5 main groups of pain types covering most of the items used frequently in other instruments (DN4 or NPSI). Pain at and below SCI level is considered in specific subscales enabling a more specific exploration of the properties of the EuroDoMed are good and support the use of this new instrument to explore neuropathic pain in patients with SCI, although an effort should be made to shorten it without losing precision.