their characteristics and monitor treatment and outcomes. The system allows longitudinal entry of well-known Patient Reported Outcome instruments (e.g. QOLIE-31-P, HADS), treatments, symptoms, and seizure frequency and severity. **RESULTS:** By September 2010, 2613 patients had registered; 1838 (70.3%) patients with a reported diagnosis of epilepsy were analyzed. The PatientsLikeMe® Epilepsy Community tends to over-represent females compared with PharMetrics® (71.7% vs. 53.6%) and 20–50 year old patients, reflecting online user demographics. The proportions of treated patients receiving polytherapy or newer AEDs were also greater in PatientsLikeMe® versus PharMetrics® (53.4% vs. 29.2%; 82.4% vs. 66.4%, respectively). Regional coverage of PatientsLikeMe® members appeared closer to US census than PharMetrics®. Patient-reported data from PatientsLikeMe® reflected the significant burden of epilepsy on patients' lives. Patients experiencing ≥1 seizure during the last 4 weeks reported significantly lower quality of life (QoL) and higher levels of depression and anxiety than those not reporting seizures (all p-values <0.005). This was even more pronounced in patients reporting ≥1 generalized tonic-clonic seizure (all p-values <0.001). Driving status was clearly impacted by epilepsy; 50.6% in the PatientsLikeMe® sample did not drive (86.2% of these because of epilepsy) and 37.4% of drivers limited their driving because of epilepsy. Patients with driving limitations reported lower health-related QoL and higher levels of anxiety and depression (all p-values <0.0001). **CONCLUSIONS:** By sharing their records online, members of the PatientsLikeMe® Epilepsy Community provide researchers with a unique source of information. Exploring these data provides insight into the disease burden, treatment patterns and associated outcomes. UCB-sponsored.

PND44

HEALTH-RELATED QUALITY OF LIFE IMPROVEMENTS WITH DYSPORT IN CERVICAL DYSTONIA

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In a multicenter, double-blind trial, Dysport 500 units was compared to placebo in the treatment of cervical dystonia. The primary efficacy response was evaluated using the Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS). Pain was evaluated with the Pain subscale of the TWSTRS and a self-reported pain visual analog scale (VAS). HRQL was assessed using the SF-36 Health Survey (SF-36). **OBJECTIVES:** To evaluate improvements in health-related quality of life (HRQL) with in patients with cervical dystonia enrolled in a randomized clinical trial with Dysport™ (also known as abobotulinumtoxinA for Injection in the United States). **METHODS:** Eighty patients were randomly assigned to receive one treatment with Dysport 500 units or placebo. Participants were assessed at baseline and weeks 2, 4, 8, 12, 16, and 20 after treatment. To evaluate HRQL, changes from baseline to Week 8 on the 8 SF-36 domains, the TWSTRS Pain subscale, and the pain VAS were compared. **RESULTS:** TWSTRS total scores were significantly improved with Dysport at weeks 4, 8, and 12 ($P \leq 0.013$ when compared with placebo). Improvements from baseline to week 8 were seen for all 8 SF-36 domains in the Dysport group. The largest improvements occurred in the Role–Physical and Bodily Pain domains. The placebo group showed some decrease (worsening) in Physical Functioning and little to no change in other SF-36 domains. The differences in mean change scores were statistically significant between the Dysport and placebo for 5 of the 8 domains (Physical Functioning, Role–Physical, Bodily Pain, General Health, and Role–Emotional [$P \leq 0.03$ for all]). Improvement in the Bodily Pain domain was also supported by significant improvements in the TWSTRS Pain subscale and the pain VAS at week 4. **CONCLUSIONS:** The data suggest that HRQL is improved with Dysport, particularly pain improvement and in the SF-36 Physical Functioning and Role–Physical domains.

PND45

ONE YEAR OF NATALIZUMAB TREATMENT IS ASSOCIATED WITH AN IMPROVEMENT IN HEALTH-RELATED QUALITY OF LIFE IN MULTIPLE SCLEROSIS PATIENTS

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OBJECTIVES: To assess the change in general health-related quality of life (HRQoL) of multiple sclerosis (MS) patients after one year of natalizumab treatment in the usual care setting. **METHODS:** MS patients, newly initiating natalizumab, were recruited to participate in a longitudinal observational study to assess general HRQoL using the SF-12v2 prior to natalizumab initiation (baseline, BL) and after the 3rd, 6th and 12th infusions. Higher physical component summary scores (PCS) and mental component summary scores (MCS) on the SF-12v2 indicate better HRQoL. Statistical regression models were used to evaluate changes in PCS and MCS scores from BL through the 12th infusion after controlling for BL covariates such as age, years since MS diagnosis, number of natalizumab infusions received, disability and functional status, number of MS drugs used prior to natalizumab and comorbidity burden. **RESULTS:** Data for 324 patients who completed the baseline through 12th infusion assessments are reported. The mean age was 46.5 (SD=10.4) and the majority of patients were female (77.8%). The mean number of years since MS diagnosis was 10.16 (SD=8.23). The adjusted PCS score improved significantly from baseline (BL 34.25, 12th infusion 36.66; p<0.001); similar significant improvements were observed in the adjusted MCS scores (BL 43.13, 12th infusion 46.77; p<0.001). **CONCLUSIONS:** Patients reported improvements in general HRQoL measures after one year of natalizumab treatment in the usual care setting. These results are consistent with results from pivotal clinical trials and document the beneficial impact of natalizumab on HRQoL in MS patients.

PND46

THE IMPACT OF EPILEPSY ON ADULT AND PAEDIATRIC PATIENT'S LIVES: A CONCEPTUAL MODEL

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OBJECTIVES: To develop a single conceptual model of the impact of epilepsy on adult and pediatric patients with partial onset seizures to guide the identification of endpoints in clinical trials of new anti-epileptic treatments. **METHODS:** A literature review to identify qualitative research investigating the impact of partial onset seizures on adult and paediatric patients' lives. Structured Embase/Medline searches identified 167 abstracts which were screened to identify primary qualitative research among adult and/or pediatric epilepsy patients. Publications were excluded if they: did not include partial onset seizure patients (with or without generalised seizures); focused on surgical treatment, were not qualitative research; were conducted outside of North America/Europe; focused on epilepsy as a secondary condition. 12 adult and 8 pediatric qualitative studies were identified. Relevant data were extracted into structured tables. Results from both samples were synthesised into a conceptual model by two experienced qualitative researchers. **RESULTS:** Twenty-three concepts were identified from the reviewed literature. Concepts were largely universal between adult and pediatric patients, although content of concepts varied between adults and pediatric, for example paediatric relationship concerns were focused on rejection in friendships and trouble developing relationships. For adults the concerns were problematic relationships with spouse or partner, fulfilling family roles and problems having children. **CONCLUSIONS:** The conceptual model identifies important impacts of epilepsy from the patient perspective. The model also demonstrates areas of patients' lives that may potentially be enhanced through improvement of epilepsy symptoms. As a result, the model allows for concepts of concern to both adult and pediatric patients to be identified and explored as potential patient-reported endpoints in clinical trials of new antiepileptic treatments.

PND47

THE HEMOPHILIA UTILIZATION GROUP STUDY (HUGS-VB): HEALTH-RELATED QUALITY OF LIFE IN HEMOPHILIA B

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OBJECTIVES: To describe health-related quality of life (HRQoL) and health utility of persons with hemophilia B, and to determine the association of these measures with self-reported joint pain and motion limitation. **METHODS:** The prospective, longitudinal Hemophilia Utilization Group Study (HUGS-Vb) recruited participants with hemophilia B from six U.S. Hemophilia Treatment Centers from June 2009 to September 2010. At initial interview, participants or their parent(s) answered questions regarding demographic and clinical characteristics, HRQoL, health utility and self-reported joint pain and motion limitation. HRQoL measures included Short Form-12 (SF-12) for adults and PedsQL for children. Health utility measures used were EQ-5D (adults) and visual analog scale (VAS). **RESULTS:** Seventy-seven participants (48% adults) were recruited. Adult mean SF-12 mental (MCS-12) and physical (PCS-12) component scores were 54.3 (±6.13) and 47.1 (±11.1) respectively. Participants with mild/moderate hemophilia (mean=50.4±9.0) had significantly better PCS-12 scores than those with severe hemophilia (mean=42.6±12.4) (P=0.0390). Mean EQ-5D and VAS scores were 0.85 (±0.16) and 85.5 (±11.1) respectively, with no significant differences between severity groups. PCS-12 and EQ-5D each negatively correlated with self-reported joint pain (PCS-12:P<0.0001, EQ-5D: P=0.0017) and motion limitation (PCS-12:P<0.0001, EQ-5D:P=0.0081); better HRQoL was associated with less severe pain or limitation. Pediatric mean total PedsQL score was 85.6 (±11.2) with physical (PF) and psychosocial functioning summary scores of 92 (±14.9) and 82 (±13.1) respectively. Mean VAS score was 88.6 (±14.3). No significant differences were found between severity groups. PF and VAS scores each negatively correlated with self-reported joint pain (PF:P=0.0127, VAS: P=0.0245) and motion limitation (PF:P=0.0009, VAS:P=0.0015). **CONCLUSIONS:** While previous HRQoL studies have examined hemophilia A and its associated clinical aspects, this is the first focusing on the hemophilia B population. As hemophilia A and B may have different clinical manifestations, HRQoL data on hemophilia B can help define disease burden in this group. One limitation is the current small sample size, which will increase as additional participants continue to be enrolled.

PND48

MEASUREMENT CHARACTERISTICS OF THE SF-36 IN CHRONIC NEUROMUSCULAR DISORDER

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OBJECTIVES: Quality of life (QoL) remains an important consideration in the care of patients presenting with chronic neuromuscular disorder (NMD). The factor structure of the SF-36 was evaluated in patients with NMD in order to determine the appropriateness of this instrument to assess QoL in this clinical population. **METHODS:** Confirmatory factor analyses were conducted on self-report SF-36 data from 245 individual's diagnosed with NMD. Six structural models of the SF-36 were evaluated against data. **RESULTS:** The underlying factor structure of the SF-36 in NMD was observed to be consistent with contemporary theoretical models of the instrument. The traditional measurement model of SF-36, however, performed comparatively poorly. **CONCLUSIONS:** The use of the SF-36 in individuals with