the operating principles and protocols for collection, retention, retrieval, and analysis of demographic information, signs and symptoms—including laboratory findings—and the response to enzyme replacement therapy with agalsidase alfa in patients with a confirmed diagnosis of Fabry disease. RESULTS: As of December 2007, 190 centres have enrolled 1453 patients from 19 countries worldwide (754 females, 699 males). Of these, 133 are girls and 118 boys less than 18 years of age. Data from these patients have added significantly to our understanding of Fabry disease, with 24 peer-reviewed publications describing the pre-treatment characteristics of the disease and the response to agalsidase alfa. Problems encountered include: 1) incomplete ascertainment of patients with different manifestations of Fabry disease; 2) some systematic lacunae in the data; and 3) uncertainty about the quality of some data. Progress has been made in overcoming these problems by: 1) convening regular meetings of investigators to review protocols, data collection, and findings from data analysis; 2) focusing on ‘core data’; 3) concentrating on achieving comprehensive data collection from centres where enrolment is especially high; and 4) employing clinical research associates to increase data collection and ensure data quality.

CONCLUSIONS: FOS has contributed significantly to the understanding of the clinical features of Fabry disease in patients of all ages. Problems with data collection and quality have been addressed by a multi-faceted approach, including focusing on a core panel of data to be collected, together with the use of clinical research associates to check data completeness and quality.

**TRENDS IN THE PREVALENCE OF AUTISM SPECTRUM DISORDERS AND RELATED HEALTH CARE UTILIZATION AND COSTS IN A STATE MEDICAID PROGRAM**

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**OBJECTIVE:** Over the past decade, there has been a tremendous increase in the prevalence of autism spectrum disorders (ASD) in the United States. With increasing ASD prevalence, the health care utilization and costs associated with these neurodevelopmental disabilities are also expected to increase. The purpose of this study is to determine the trends in the prevalence of ASD and ASD-related health care utilization and costs among recipients enrolled in a state Medicaid program.

**METHODS:** A retrospective descriptive analysis of a state Medicaid fee-for-service administrative claims dataset was conducted. Medical services claims with a primary, secondary, or tertiary diagnosis code of ASD (ICD-9-CM 299.0/299.8) were extracted to determine the prevalence of ASD. Claims for psychotropic medications prescribed to recipients with ASD were then extracted using de-identified unique recipient numbers obtained from the medical services claims. Prevalence and health care utilization numbers and rates were reported by demographic categories. Costs were reported from the state Medicaid perspective.

**RESULTS:** Between 1996 and 2003, the number of recipients identified with ASD increased from 246 to 1399, respectively. In terms of age distribution, recipients in the age group 6–14 years represented the highest proportion in all the study years, with the proportion increasing from 38.6% in 1996 to 47.0% in 2003. A majority of the recipients with ASD were males, who made 69.1% of the sample in 1996 and 74.6% in 2003. Whites constituted a majority (>90%) with respect to ethnicity in all the study years. The increase in the prevalence of ASD was accompanied by an increase in ASD-related health care utilization and costs.

**CONCLUSION:** Similar to national trends, the prevalence of ASD increased considerably over the years in the state Medicaid program. In addition, the prevalence of ASD among Medicaid recipients varied by demographic characteristics. The study provides useful data to better serve the needs of this growing population.

**TRENDS AMONG HOSPITALIZED CYSTIC FIBROSIS PATIENTS**

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**OBJECTIVES:** Few studies have evaluated trends among inpatients with cystic fibrosis. The purpose of this paper is to explore patient demographics, diagnosis, and procedures to gather a general picture of cystic fibrosis treatment. Exploration of the cystic fibrosis data set to find trends among the variables, race, gender, mortality, total charges, length of stay, age diagnosis, and procedures provides insight into better methods to treat individuals with cystic fibrosis.

**METHODS:** The data used were taken from the National Inpatient Sample (NIS). The cystic fibrosis data set was formed by isolating the NIS patients diagnosed with cystic fibrosis, using a 10% sample from 2004. The cystic fibrosis data set contained 1582 observations. Descriptive statistics were used to examine the data; chi-square tests and logistic regressions were employed to analyze the data.

**RESULTS:** Statistics showed that patients with a longer length of stay were more likely to die during hospitalization and to be older. Most races had two high density ages; one around 20 years of age and the other around 60 years of age with the exception of African Americans and Native Americans. The three procedures: transfusion of packed cells (ICD-9 99.04), continuous ventilation <96 consecutive hours (ICD-9 96.71), and endotracheal tube insertion (ICD-9 96.04) and two diagnoses pneumonia (ICD-9 486) and amyloidosis (ICD-9 277.3) accumulate deposits of abnormal proteins) were found to be directly related to mortality. The data also showed that none of the patients with esophageal reflux (ICD-9 530.81) died during hospitalization.

**CONCLUSIONS:** From the results, older patients, patients with long lengths of stay, or those diagnosed with amyloidosis could be considered high-risk for hospital mortality. However, these results are limited; no information about outpatient factors, medications, or test results could be assessed. Also, there were few patients who died during hospitalization on which to base the analysis.

**SUBSTANCE ABUSE AMONG PATIENTS DIAGNOSED WITH INSOMNIA**

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**OBJECTIVE:** To assess the rate of substance abuse among insomnia patients prescribed nonbenzodiazepine receptor agonists (nBZRAs), benzodiazepines (BZDs), and melatonin receptor agonists (MRAs). **METHODS:** This analysis used a retrospective matched cohort design with data from Florida Medicaid recipients 18 to 64 years old. Patients initiating nBZRA, BZD, or MRA therapy between July 1, 2002 and March 31, 2006, without a history of substance abuse, were included in this analysis. One MRA patient was matched to three nBZRA, BZD, or MRA patients based on demographic and clinical (history of insomnia, depression, anxiety) characteristics. Service dates and days of medication supply variables from pharmacy claims established periods of treatment exposure, while substance abuse related to sedatives and hypnotics was identified using International Classification of Diseases 9th edition Clinical Modification (ICD-9-CM) codes for the same time frame. Rates of substance abuse (SA) were calculated as the number of...