Case Report of Specialty Pharmacy
Management of Hemophilia

Today it is generally understood that a disproportionately high share of medical claims are attributable to a small minority of patients with rare chronic disease states. Hemophilia is considered to be one of the most expensive chronic conditions currently being treated by any health care system. Antihemophilic medications have been estimated to account for greater than 90% of the total costs of hemophilia care.1 The annual cost of medications to treat a patient with severe hemophilia may exceed $300,000 per year.2

Adherence to antihemophilic medications has been defined as infusing 75%-80% of prescribed doses.3 Noncompliance with these medications can contribute not only to poor outcomes, but also to significant costs associated with excess inventory. An average adult with severe hemophilia that is infusing 3,000 units 3 times per week as prophylaxis can accumulate 72,000 units of unused factor over the course of 1 year by missing 2 doses per month, or possible waste valued at $96,480 in antihemophilia drug cost (priced at 80% of average wholesale price [AWP] in January 2011).

Our specialty pharmacy developed a disease management program for hemophilia modeled after the results from the Haemophilia Utilization Group Study (HUGS).2 The program is designed to provide intensive patient management to improve clinical outcomes and to lower hemophilia-related health care costs. Our program was adopted by a 1.4-million member West Coast health plan in October of 2009 to serve its hemophilia population. At the initiation of this outcomes program, 54 unique patients were identified as potential candidates for the program. Each patient case was carefully evaluated to ensure appropriate utilization of health care resources and to achieve maximum benefits for the health plan. All patients with severe disease were selected as candidates. Other variables included: number of bleeds per year, age, comorbid conditions, annual factor consumption, and number of target joints. At the end of this screening period, 37 of the 54 patients were identified as candidates based on disease severity. Patient participation was optional, and 24 of the 37 patients (65%) elected to participate in our disease management program.

One of the 24 enrolled patients was a 21-year-old male with severe hemophilia A. His disease was complicated, with multiple target joints, obesity, noncompliance, and a general lack of knowledge regarding his disease and treatment. He had a treatment regimen consisting of clotting factor Kogenate FS as primary prophylaxis and as needed for bleeding episodes. His social situation was problematic including a dual residence, unemployment, and a sedentary lifestyle. He did not use alcohol or illicit drugs. On admission to the program, the patient completed a detailed telephonic assessment by a hemophilia specialist and hemophilia self-management questionnaire. We then began the disease benchmarking period where it became apparent that his disease severity, bleeding history and utilization were not congruent. This patient averaged 1.75 bleeds per month into his target joints which included both knees and elbows. A home visit by a hemophilia nurse specialist was scheduled to assess the patient.

On the day of the home visit, the patient presented with a notably swollen and painful right knee, bruised and swollen knuckles on both hands, and a recovering bleed in his left forearm. He also presented with limited range of motion in his right knee and left elbow. The patient admitted to discontinuing his primary prophylaxis and treating only the most severe bleeds; he believed that he could over time desensitize his body to the exogenously administered clotting factor, reducing his requirements and possibly the number of bleeds. Additionally, the patient treated his severe bleeds with a single dose of double the prescribed units. He assumed this would stop the bleed quickly and prevent its reoccurrence. This patient interview solidified our initial assessment of a lack of disease knowledge and noncompliance. The patient had an on-hand inventory of over 45,000 units and another 30,000 units at his alternate residence; this was nearly a 2-month supply of clotting factor at an estimated drug cost of $100,500 (priced at 80% of AWP).

The patient was receptive to the hemophilia nurse specialist and was eager to ask questions about his condition. He received education focusing on his disease severity, the mechanisms of joint destruction from bleeds, and the consequences of treatment delays and noncompliance to his prophylaxis regimen. Visual aids were used throughout this process. A treatment plan was developed and discussed with the patient, and he agreed to resume his prophylaxis treatment. He verbalized satisfaction with the therapy management program and agreed to continue enrollment. As part of the disease management program, the patient receives monthly telephonic assessment calls to capture self-reported bleeding episodes and other lifestyle indicators. Three months after the nurse visit, the patient demonstrated compliance with his treatment plan. The patient’s telephonic self-assessments indicated an increased level of compliance with his prophylaxis that is also confirmed by his factor utilization history. Bleeding into his target joints was reduced to 1 episode in the 3-month post intervention period. The patient also reported wearing his medical alert identifier. In addition to improved care management, the intervention with the nurse visit reduced the average monthly hemophilia drug cost by $6,490, from $225,832 in the 5 months before the intervention to $193,382 in the 5 months after the intervention.

Aggie Gilbert, RN
Hemophilia Clinical Nurse Specialist

Brian Tonkovic, PharmD
Clinical Manager, EyeOn Therapy Management
Coram Specialty Infusion Services Therapy Management
tonkovicb@coramhc.com
### Disclosures
Gilbert and Tonkovic are employees of Coram Specialty Infusion Services Therapy Management.

### References

### Online Drug Pricing Tools Deserve More Attention
We read with great interest the article “Evaluation of health plan member use of an online prescription drug price comparison tool” by Carroll and colleagues. The research shows how drug information tools are being used by consumers. We (DestinationRx) have been creating innovative drug and plan comparison tools for more than a decade. In the spirit of disclosure, DestinationRx’s Drug Compare and its predecessor Rxaminer are tools that compete with RxEOB, the online tool that was the subject of the study by Carroll and colleagues. We make available drug pricing tools to more than 100 million Americans, and as such we have comments on 3 points that your readers may find helpful.

First, while we do have a consumer version of Drug Compare that shows drug costs based on estimated community pharmacy prices, the vast majority of our users are accessing plan- and/or PBM-sponsored sites. These sites come loaded with member-specific benefit information including formulary, utilization management restrictions, drug tiers, member copay and pharmacy-specific price comparisons. Second, Carroll and colleagues found that approximately 5.2% of families in a large integrated health plan who used the pharmacy benefit throughout the year used the MyPharmacyTools (RxEOB) online pricing tool in a 12-month period from July 2007 through June 2008. We found that 5.8% (n=4,087) of approximately 71,000 employees enrolled in health savings accounts used our Drug Compare online tool in a 9-month study period through October 2010.

Third, we agree that drug pricing is of paramount concern to end-users. We believe that filtering the alternatives displayed based on comparative efficacy leads to even greater adoption and behavior change. It is for this reason that we always emphasize that beyond pricing it is imperative to display therapeutic alternatives of similar efficacy.

Our experience shows that drug costs are still one of the most controllable of all health care expenditures, and we are glad to see drug information tools getting the visibility they deserve for allowing members to better manage their health care and drug spend.

Alexander Grunewald, PhD
DestinationRx
Los Angeles, California
alexander.grunewald@drx.com

### Disclosures
Grunewald is employed by DestinationRx.

### References