



**GLOBAL HEALTHY LIVING
FOUNDATION**
YOUR HEALTH. YOUR HAPPINESS.

Patient Perspectives on Medication Switching for Non-Medical Reasons

A Survey of Stabilized Patients by the Global Healthy Living Foundation

April 23, 2015



Patient Perspectives on Medication Switching for Non-Medical Reasons

A Survey of Stabilized Patients by the Global Healthy Living Foundation

Overview and Methodology of the Global Healthy Living Foundation Survey

Patients with complex chronic diseases who have stabilized their condition through biologics—an expensive injected or infused drug, created from biological sources, used to treat conditions such as rheumatoid arthritis and cancer, are concerned that insurance plan requirements may soon jeopardize patient health and undermine treatment decisions made by patients and their doctors. These drugs have dramatically improved patient quality-of-life, stopping disease progression and sometimes achieving disease remission. Pharmacy benefits managers (PBMs) and payers can force stabilized patients to change their medications without notifying the patient and provider. This is done by requiring that the medicine originally prescribed for a patient be changed to a preferred alternative on an insurance company's drug formulary in an effort to contain or reduce insurance company costs. Frequently the switch is made without the prescribing provider's permission and knowledge, and the patient may or may not be alerted by the pharmacist.

There are several potential health and financial consequences that can result from medication switching for non-medical reasons. The primary risks to patient health are twofold: the medication could be less effective than what the physician prescribed, and there could be new negative side effects. These potential consequences would occur because the substituted drug has different active ingredients and mechanisms-of-action. The possible financial consequences of medication switching on patients if the new drug fails include more visits to emergency care facilities, increased numbers of visits to physicians or hospitals, and/or lost worker productivity. Conversely, if a physician-prescribed drug is switched and the switched drug is successful, the physician won't know it and may continue prescribing an ineffective drug.

To better measure patient perceptions of and experiences with such practices, the Global Health Living Foundation (GHLF) conducted a survey about the impacts of switching patients with a chronic autoimmune disease who are currently stable on a biologic therapy.

GHLF administered survey questions through a web-based tool to 177 members of CreakyJoints, a GHLF community of arthritis patients. These patients were currently stabilized on their biologic therapy and living in the United States. The survey questions were divided up according to the potential medical, financial and emotional impact from medication switching. Each of these sections had different multiple choice, yes or no, and/or free-form response fields for each question throughout the survey.

Executive Summary of Survey Findings

Stabilized arthritis patients nearly universally disapproved of switching biologic medicines without patient and provider consent. A total of 98 percent of survey respondents support legislation that would specifically prohibit PBMs or pharmacists from switching a patient's biologic medicine without patient or provider notification.



The survey also revealed that 95 percent of respondents were concerned their disease would worsen if their biologic medicine were switched. 93 percent of respondents who have tried multiple biologics said they do not believe all biologics are equally effective. Of the patients surveyed, 72 percent reported they have been on their current biologic for at least one year; 31 percent have been on their current biologic for more than three years. About 35 percent of respondents indicated they need to visit an infusion center to administer their medicine while 60 percent self-inject. When patients switched their treatment, 79 percent of respondents said it was because the biologic was “*not effective*.” 68 percent of respondents have tried at least one other biologic medicine before finding their current, effective medication, and 26 percent have tried three or more biologics before settling on their present treatment. About 88 percent of the time it took patients more than one year to find the biologic medicine that worked for them, with 30 percent of respondents reporting they have waited at least five years to find an effective biologic for their respective condition.

The survey also addressed financial implications for stabilized patients in various switching scenarios. 86 percent said they would stay on their same biologic if there were a 20 percent price increase, rather than switch to a less effective biologic, even if the new drug had fewer side effects. Likewise, 77 percent of patients acknowledged that if their current biologic increased in price by 20 percent, they would still not be willing to switch to a cheaper biologic that had greater effectiveness if it carried more severe side effects.

When asked how their out-of-pocket costs would be affected if their current biologic's cost were increased by 20 percent, 42 percent of respondents said they would have to “*Reduce other essential spending*,” compared to 31 percent who would “*Seek less costly options*” and 21 percent who reported the price spike would have “*No impact*.” Additionally, 54 percent of patients said cost did not come into consideration when their physician prescribed the treatment.

The survey asked stabilized patients who they thought should have a say in prescribing and treatment decisions; 86 percent of respondents said patients and 90 percent said doctors. These answers contrasted sharply to the 7 percent of respondents who said pharmacists and 2 percent who said insurers should have a say in the matter. Additionally, 20 percent of respondents have already been hurt by switching biologics and provided open-ended answers describing how they felt about the side-effects caused by medication switching.

Conclusions from Survey Findings and Recommended Policy Action

This survey demonstrates that stabilized arthritis patients have many concerns about switching to a new biologic therapy. Nearly all patients surveyed expressed concern that their condition will worsen if they are switched to a new biologic medicine. A majority of respondents indicated that if the price of their biologic increased they would be willing to incur financial costs to remain on their current treatment.

An overwhelming majority of patients surveyed intimated that the decision to prescribe a biologic medicine should remain in the hands of patients and their physicians, while only 2 percent of respondents thought insurers should make this decision.



Based on the answers and data determined from this survey, GHLF recommends the following policy action be taken to help protect stabilized patients from being switched by insurers or pharmacists:

- ✓ Enact legislation that would **prohibit an insurance company from removing biologics used to treat autoimmune diseases from their formulary** without offering a “grandfathering” option for stabilized patients.

If this measure is implemented by regulators and policymakers, patients with chronic illnesses who have stabilized their conditions will be protected from unnecessary, unfair and potentially dangerous medical switching.

About the Global Healthy Living Foundation

The Global Healthy Living Foundation (www.ghlf.org) is a 501(c) (3) non-profit organization, based in New York, with the mission to improve the quality of life for people with chronic illness. GHLF accomplishes its mission by advocating for improved access to care and by educating the community about the importance of diagnosis, early and innovative medical intervention, long-term lifestyle improvement, and therapeutic compliance. Co-founded in 1999 by arthritis patient and advocate Seth Ginsberg (diagnosed with Spondyloarthritis at age 13), GHLF includes disease-specific communities, the most visible being CreakyJoints (CreakyJoints.org), a network of nearly 80,000 arthritis patients and caregivers. Under a contract from the Patient Centered Outcomes Research Institute, CreakyJoints is creating the country’s largest patient registry of people with arthritis.

About CreakyJoints

CreakyJoints, part of the not-for-profit Global Healthy Living Foundation, is a dynamic support, education and advocacy organization, with a sometimes irreverent tone, for people with all forms of arthritis and rheumatic disease. Founded in 1999, today CreakyJoints is more than 80,000 strong. CreakyJoints works to create an environment where strength, experience and information can be exchanged to improve quality-of-life through educational programs, supportive social media, smartphone apps and in-person events. More recently, CreakyJoints has emerged as a powerful research network, anonymizing its vast online community to inform the medical and scientific communities about the wants and the needs of the de-identified patient community under a contract from the Patient Centered Outcomes Research Institute.



Global Healthy Living Foundation
515 North Midland Avenue
Upper Nyack, New York 10960 USA
+1 845 348 0400
+1 845 348 0210 fax
www.ghlf.org

