EVIDENCE BASED ADVOCACY: A CASE STUDY
Seth D. Ginsberg, GHLF Co-Founder

Organization

Dedication...

Organization

50-State Network

- Members:
  - 350+ Patients
  - All 50 States (and Puerto Rico)
    - Geo-specific to state capitols
- 120+ individual medical conditions

Engagements:
- Public testimony
- Interviews with the media
- Letters to the editor and op-eds
- Ongoing training calls and webinars
- Social media
- Strategic outreach to key decision makers

GHLF's 50-State Network is about transforming pain into purpose, empowering those that may feel victimized by disease. Our focus is on repurposing the energy of frustration, despair, and helplessness into positive mobilization, action, and fair representation to benefit all of us.

Current State Engagements

- Delaware
- Indiana
- Massachusetts
- North Dakota
- Virginia
- Colorado
- Washington
- New York
- Illinois
- Louisiana
- Maryland
- California
- Texas
- Pennsylvania
- Idaho
- New Jersey
- Oregon
- Kentucky
- Utah
- Puerto Rico
Advocacy Areas:

- Insurer utilization Management
  - Fail first
  - Step therapy
  - Prior authorization
  - Specialty tiers
  - Clinical pathways
- Formulary reduction
  - Non-grandfathering
  - Switching stable patients
- Biosimilars naming
  - Distinguishable names (World Health Organization)
  - Biosimilar Labeling, Biosimilar Indication Extrapolation
- Biosimilars substitution

Background: Switching Study (2015)

What prompted the study?
- Pharmacy Benefit Managers (PBM’s) historically have forced patients to change their therapy based on an insurance company’s drug formulary.
- Formularies typically get switched year-to-year, however the impact on patients is not considered or incorporated into that decision.
- Evidence is needed to argue the emotional, financial and medical impact of these switches.

Case Study: Switching Study

- Who was the target audience of study results?
  - Policymakers – state and national
  - Regulators – state and national
  - Private payers / insurers (PBM’s)
  - Earned and social media outlets
- Multi-sponsor study for maximum credibility:
  - Amgen
  - AbbVie
  - GHLF

Study Overview

How we structured the study:
- 28-item online survey
- 600+ patients screened, 177 eligible who completed the survey
- Self-reported patients who are currently prescribed a biologic and considered “stabilized” (i.e. being happy with both the progress and results of their current treatment).
  - >50% did not consider themselves “stabilized”

Study Results

- Patients have real fears about being forced to switch.
- Patients do not believe that all biologics are equally effective at treating their disease.
- It takes time for patients to find the right biologic.
- Patients value treatment effectiveness over cost considerations.
- Patients strongly resist being forced to switch to another biologic, even if it is less costly, more effective or has fewer side effects.
- Patients are deeply connected to their own care and have strong feelings about who should play a role in their treatment decisions.
Study Impact

- What did we do with the study?
  - Congressional briefing
  - Earned media
  - Social media
  - State advocate education (talking points)
    - State legislators
  - Regulators
  - Private payers

Study Impact

Chronically Ill Patients Fearful of Unreported Drug Switching By Insurers and PBMs

“Insurers and pharmacists should not switch effective therapies without patient and physician notification, according to a national survey of stabilized autoimmune patients.”
Benefits:

- Happier patients and their caregivers.
- Improved safety and security – for office and user.
- Efficient delivery channel for relevant (geo-specific) health education and advocacy outreach.
- Opportunity for future patient-office connectivity (intake forms, syncing with E.H.R., etc.)

Customized Landing Page (Example):

THOUGHTS? COMMENTS? QUESTIONS?

Sginsberg@GHLF.org
914-393-7800