Women In Government
6th Annual Healthcare Summit
Washington, DC
CreakyJoints at WIG

- **Who We Are**
  - Our inspiration and purpose
  - 50-State Network Equipped and Defined

- **Walking the Walk**
  - 50-State Network’s 2015 Mobilization
  - With Recognition Comes Responsibility

- **How We See the Future of Advocacy**
  - Moving beyond anecdotes: A case study in data driven advocacy
  - Harnessing new tools
  - Connecting to patients using innovative approaches
CreakyJoints Member Profile:

- Patients, Healthcare Professionals, and Caregivers
- 90,000+
- Age: 51 years old (+/- 12 years)
- Female: 94%
- Insurance Coverage:
  - Private (62%)
  - Public (18%)
  - Private & Public (12%)
  - Not Covered (8%)
50-State Network: Grassroots Advocacy

- 2015: **395** Advocates in all **50** States
- [www.50StateNetwork.org](http://www.50StateNetwork.org)
- Areas of focus:
  - Immunology (RA/PsA/AS)
  - Gout
  - Opioid-Induced Constipation
  - Vaccinations (Meningitis B)
50-State Network: Equipped and Defined

• **One-on-one calls**
  - Goal: Learn about why patients sign up and what their advocacy interests are

• **Monthly Teleconferences**
  - Goals:
    - Address patients’ advocacy interests
    - Build community
    - Peer to Peer sharing and support
    - Provide Advocacy Training
      - Finding your voice
      - Social Media 101
      - Speaking with Media
      - How to connect with an audience

Dear Advocates,

We hope you had a great Labor Day weekend! Please join us for our next 50-State Network teleconference this Thursday, September 10th at 8:00 PM ET/ 5:00 PM PT.
50-State Network: Monthly Curriculum

- **January**: Get to know your legislator
- **February**: Social Media & Advocacy with Digital Communications Manager Michelle Thai
- **March**: How to Testify with Patient Advocate Tabatha
- **April**: Learn How To Meet Your Representative With Policy and Gov. Affairs consultants Jennifer Leib & Megan Brooks
- **May**: Research & Advocacy with Dr. Ben Nowell
- **June**: Media 101 training with Jessica Daitch, Public Relations Consultant
- **July**: Motivate your Legislator with NY Assemblywoman Ellen Jaffee and her Chief of Staff Tiffany Card
- **August**: Legislative Case Studies with Patient Advocates Kat Macfarlane & Mickey Goodwin
- **September**: Middlebury Internship
- **October**: Invite a friend
50-State Network: New Website

- **Platform for patients to:**
  - Learn about different advocacy issues
  - Obtain policy resources
  - See the network’s collective work and learn about what others like them are doing to advocate
  - Aggregate media related to our patient advocacy work
  - View and support legislation
    - Sign-on letters

- **Scalable for co-morbidity (additional conditions) advocacy**
50-State Network: New Website

We Need Your help as a 50-State Network Advocate!

Now is your time to be heard

Join the 50-State Network here

Advocates Like You

Click each photo to learn more...
50-State Network 2015 Mobilization

- **Biosimilar Substitution/Notification**
  - Colorado (*testified twice*)
  - Georgia
  - Illinois (*testified*)
  - Idaho (*testified*)
  - Louisiana (*testified twice*)
  - New Jersey (*pending signature, testified twice*)
  - North Carolina (*testified*)
  - Tennessee
  - Texas (*testified twice, hill day*)
  - Utah (*testified*)
  - Washington (*testified*)
  - Puerto Rico

- **Fail First/Step Therapy**
  - Member of NY advocacy coalition planning committee
  - Participated in Albany advocacy/education day
    - Media briefing
    - Meetings with key legislators
  - Media education and engagement with advocates in Atlanta, GA
  - Social media support for FL and NC coalition campaigns
  - Collaboration with American Academy of Pain Management State Pain Policy Advocacy Network to reach consensus on unified state legislative positions

Legislation enacted (18 + Puerto Rico)
Board of Pharmacy regulation (1)
Legislation is active and progressing (2)
Over 237 Million Media Impressions January – October 2015

*Includes all CreakyJoints, Arthritis Power and Advocacy media; Estimates courtesy of Cision
Evidence-based Advocacy

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.
Background

• How did we approach the study?
  • We designed a study to examine patient perceptions of the impact of possible forced medication switching in a sample of stable patients with a chronic autoimmune disease taking biologic medicine.
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
Combining Tactics to Scale Impact and Reach

93% of respondents who have tried multiple biologics said they do not believe all biologics are equally effective.

- GHLF Survey on Switching

#DontSwitchMe

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Switching Hurts. Join our Congressional Briefing TODAY 4/23 Noon Eastern by following hashtag: #DontSwitchMe. #rheum

95% of stabilized patients would be concerned that their disease would worsen if their biologic medicine was switched

-CHLF Survey on Switching

#DontSwitchMe

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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.”
What’s Next?
Periscope: Bringing the Advocacy Experience to a Living Room Near You
What can you do to ensure that the patient perspective is at the center of healthcare conversations/debates?

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