

Workshop on Advocacy and Innovation

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Dialogue for Action
Advocacy and Innovation
April 22, 2015



**GLOBAL HEALTHY LIVING
FOUNDATION**

- Background
- Relatable Humanity
- Identity Crisis
- Our Platform
- What's Next?





*A free community of support and resources
for people with all forms of arthritis*

Go to www.CreakyJoints.org

MEMBERSHIP IS FREE AND CONFIDENTIAL

- ☒ **EDUCATION:** *Learn* about the latest news and information related to your condition.
- ☒ **SUPPORT:** *Meet* and talk to others within the largest arthritis online community.
- ☒ **ADVOCACY:** *Overcome* the hurdles we all face when dealing with our condition.
- ☒ **RESEARCH:** *Participate* in surveys, provide feedback, and help the world understand what you're going through.

Referred by



facebook.com/creakyjoints



@creakyjoints



Creaky Joints by the Numbers:

- Facebook: 75,108 “likes”
- Twitter: 4,000+ “followers”
- E-mail distribution list: 13,404 active contacts
 - ❖ Average open rate: 25%+
- Monthly Twitter chats (#CreakyChats)
 - ❖ First Monday of each month, average reach of 6,000 per chat
- Current detailed catalogue: 3,700 patients



Digital Advocacy = Humanity

Welcome to CreakyJoints

*A place to learn, laugh, cry, make friends, commiserate, celebrate, be cool, fall in love
—even help find a cure for arthritis*

Visit our web home: www.creakyjoints.org



Patient Powered: Patient Governors

- 12 Patient Governors (PG's) selected.
- PGs monthly conference calls, est. June 2014.
- PGs convened September 2014 NY "Summit".
- PGG Charter created.



Patient Governors:



Kelly C.
Rockton, IL



Jon A.
Olathe, KN

VICE-CHAIR



Britt J.
Burbank, CA

CHAIR



Rachelle C.-H.
Chesterfield, MI



Bryan L.
Scottsdale, AZ



Shantana H.
Bridgeport, CT



Marta G.
*Trujillo Alto,
Puerto Rico*



Jonathan H.
Santa Fe, NM



Elizabeth F.
New York, NY



Carole W.
Kona, HI



Whitney W.
Birmingham, AL



Leslie R.
New York, NY



Front Line of Patients' Questions



J.G. Chayko @jgchayko · Jan 5

#CreakyChats Sometimes get numbness in my extremities. Not cold, lack of circulation. Can RA affect the nervous system? **@CreakyJoints**



Lindy Bryant @Linsarmel · Jan 5

#CreakyChats is either plaquinil, methx (25) or Humira likely to cause globus sensation. Had for a year. Double Pariet/Nexium doesn't work.



Alan Brewington @abrewi3010 · Jan 5

Is there a connection between severe trama/bodily injury & **#RA**? Seen mixed studies. **#CreakyChats**



Recent topic posts “Tell Us What You Want to Know!”
RA: incontinence, fatigue, pregnancy, mental health



HOW CAN
YOU BE
LOST?
THIS PLACE
IS TINY!





Seth's 50 State Network

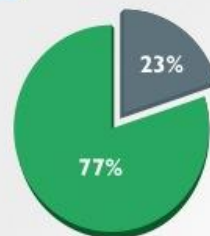


- Members:
 - ❖ 250+ Patients in 50 States
 - ❖ 24 Organization partners
 - ❖ 11 Industry Partners
- Conditions:
 - ❖ 100+ individual medical conditions
 - ❖ Rheumatoid Arthritis: 131 patients
- Data Driven
 - ❖ Geotargeting
 - ❖ Insurance type



Data Driven Advocacy

WHAT ARE THE BARRIERS TO CARE?



3rd party pays for their health insurance in 30-60 days
Pays own insurance



PRIVATE INSURANCE

Family Member's Plan
Employer
Family Member's Employer

Rheumatologist-prescribed medicine denied by insurance company

29%

If your copay was greater than \$100, you were more likely ($p < 0.05$) than people with a copay under \$100 to be denied the drug your physician prescribed.

High copay denials 49%.
Low copay denials 20%

27%

have had their insurance company replace or substitute their prescribed RA medicine without their knowledge

93%

believe they should be notified by phone or in writing if their prescribed medicine is substituted

94%

pay out-of-pocket expenses for their RA medications

31%

have had to pay an especially high (>\$100) specialty tier copay or coinsurance for an RA drug

Used a co-pay card to help manage out-of-pocket expenses for RA drugs

60%

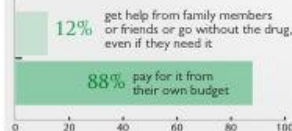
If your copay was greater than \$100, you were more likely ($p < 0.05$) to use copay cards than if it were less than \$100.

(83.0% vs. 49.6%)

90%

have never discussed the positive or negative influences that Obamacare may have had on their coverage changes

Out of the 68 people who have never used a co-pay card to help manage out-of-pocket expenses for RA drugs:



BARRIERS TO CARE

Patients identified that cost of copays was the most difficult barrier to care, followed by paperwork, insurance type hindered access, and then lack of foundation and charitable aid

| Cost of Copays | | | |
|---------------------------------------|------|------|------|
| 50.3 | 18.1 | 16.8 | 14.8 |
| Paperwork | | | |
| 25.0 | 33.3 | 18.6 | 23.1 |
| Access Hindered by Type of Insurance | | | |
| 11.8 | 27.6 | 38.2 | 22.4 |
| Lack of foundation and charitable aid | | | |
| 12.3 | 20.1 | 22.1 | 45.5 |

Most Difficult

Least Difficult



Current State Engagements



- Delaware
- Indiana
- Massachusetts
- North Dakota
- Virginia
- Colorado
- Washington
- New York
- California
- Texas
- Pennsylvania
- Idaho
- New Jersey
- Oregon
- Kentucky
- Utah
- Illinois



CreakyJoints = Innovation

What's Next?

- CreakyJoints *Wireless in the Waiting Room* pilot
 - ❖ Free WiFi in waiting room and infusion centers
 - ❖ Pilot markets: Los Angeles, Austin, Atlanta, Shreveport

