

# Social Media for Patient Advocacy

# AnneMarie Ciccarella

# Alicia C. Staley

@chemobrainfog

<http://www.chemobrainfog.com>

<http://www.linkedin.com/in/amciccarella>

@stales

[www.facebook.com/aliciastaley](http://www.facebook.com/aliciastaley)

[www.bcsn.org](http://www.bcsn.org)

[www.linkedin.com/in/aliciastaley](http://www.linkedin.com/in/aliciastaley)

# Agenda

- Overview of Social Media Tools and Techniques
- 15 min Breakout Session – New and Advanced
- Group Discussion

# Advocacy in the Digital World

- Mailings, newsletters not as effective
- New tools, new ways to communicate
- Communication needs to be timely
- Cost effective

# Why Social Media?

- Social Media shrinks the world – connections can be instantaneous
- Reach goes beyond the limits of geographic communities
- Learn from others

# Advocacy + Social Media = Perfect Match

- Targeted Messaging
- Reach new constituents
- Engage new “Ambassadors”
- Expand reach to new communities

# Three Rules for Success

1. “Never post anything you wouldn’t want published on the front page of the NY Times.”  
Assume everything is ALWAYS PUBLIC
2. Be polite and respectful.
3. Be consistent.

# Social Media Tools for Success

1. Twitter
2. Facebook
3. LinkedIn
4. Instagram/Snapchat/Pinterest

# Twitter

- Individual messaging
- Open, transparent conversations
- Follow conferences, areas of interest
- Short, concise, rapid fire
- Information sharing

# Facebook

- Open and closed groups
- More in depth conversations and discussion
- Robust information creation and sharing
- Biggest area for growth

# LinkedIn

- Connect with Congress
- Industry representatives
- Showcasing individual skills and involvement with key organizations

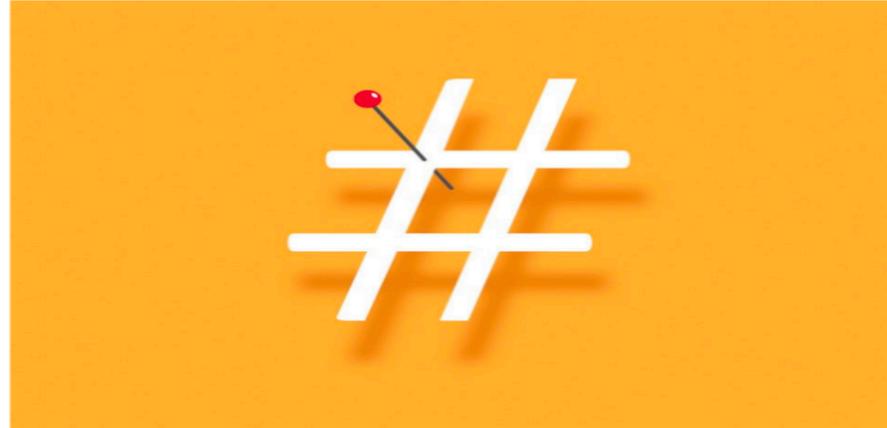
# Instagram/Snapchat/Pinterest

- Secondary information creation and sharing
- Showcase images from events
- Short form video
- Tag and pin relevant articles to share with larger audience

# hashtags

LEXI PANDELL BUSINESS 05.19.17 07:00 AM

## AN ORAL HISTORY OF THE #HASHTAG



📷 BEN WISEMAN

WHETHER YOU FIRST knew # as a number sign, the pound symbol, or a tic-tac-toe board, its incarnation as the hashtag has changed language for millions around the world. Sure, it can indicate where you're posting from ([#OvalOffice](#)) or what you're posting about ([#FakeNews](#)). But it has also shaped elections, launched social movements, and transcended its meaning as a mere keystroke to become a defining symbol of the digital age. Its story started on a bare-bones social-networking site called Twitter back in

<https://www.wired.com/2017/05/oral-history-hashtag/>

# Hashtags

#

- #CPAT17
- #Cancer
- #CancerSurvivor
- #ACA
- #AHCA

# Hashtags

**Public Posts** See All

 **Write4wellness**  
3 hours ago · 🌐

Heading to [#CPAT17](#)! Expecting to learn more about cancer advocacy!

👍 1

 **Write4wellness**  
3 hours ago · 🌐

Hello, my friends! I'm a newbie at cancer policy advocacy, and am expecting to absorb tons...[See more](#)

**D.C. – Bound!**  
[write4wellness.wordpress.com](http://write4wellness.wordpress.com)



 **Stacey Tinianov** @coffeemommy · 50m  
Patient Advocacy, Research Advocacy & now Healthcare Policy Advocacy at [#CPAT17](#) Every piece of puzzle still comes down to putting PEOPLE 1st

💬 🔄 ❤️ 3 ✉️

Lacuna Loft and 1 other follow

 **Veronika Panagiotou** @veronikap88 · 19m  
[#CPAT17](#) Here I come! Fighting for healthcare!@CancerAdvocacy @StupidCancer @communityphdppu

💬 🔄 ❤️ ✉️

 **Jen Campisano** @JCampisano · 37m  
Gearing up to speak at [#CPAT17](#). I'm nervous - my story is deeply personal, but remembering these are my ppl & trying to save healthcare is 100

💬 1 🔄 1 ❤️ 1 ✉️

 **NCCS** @CancerAdvocacy · 39m  
We are excited to welcome cancer advocates from all across the country to our annual [#CPAT17](#) Symposium today!

💬 🔄 3 ❤️ 1 ✉️

Maria Shriver and 4 others follow

 **Xenia Rybak** @xenianyb · 3h  
Heading to D.C. for [#cpat17](#). Excited to learn about [#canceradvocacy](#) and [#protectourcare](#) and to head to the hill on Tuesday.

💬 🔄 ❤️ ✉️

# #BCSM

## Breast Cancer Social Media

# #BCSM by the Topics

- **Research report**
- **Major Conferences**
  - **ASCO**
  - **ASCO Breast**
  - **ASBRS**
  - **SABCS**
- **Celebrity Effect on Breast Cancer conversations**
- **Day to Day living**
- **Finding your new normal**
- **Getting through surgery**
- **Dealing with Chemo**
- **Tips and Tricks for self-care**

# #BCSM by the Numbers

Home / Healthcare Hashtags / #BCSM / Analytics

## The #BCSM Influencers

### Top 10 by Mentions

	@drattai 18,612
	@stales 12,446
	@jodyms 11,099
	@chemobrainfog 5,739
	@xeni 3,747
	@regrounding 3,711
	@abhuret 3,156
	@danafarber 2,897
	@drbeckerschutte 2,857
	@ascopost 2,803

 Tweet 228

### Top 10 by Tweets

	@stales 8,560
	@drattai 7,940
	@jodyms 5,760
	@abhuret 3,265
	@chemobrainfog 2,696
	@drbeckerschutte 2,686
	@itsthebunk 2,251
	@chigr13 2,204
	@subatomicdoc 1,879
	@regrounding 1,835

 Tweet 228

### Top 10 by Impressions

	@stales 85,890,667
	@livestrong 57,817,807
	@drattai 55,580,954
	@jodyms 43,297,244
	@xeni 20,973,035
	@talkabouthealth 18,635,028
	@subatomicdoc 15,258,236
	@chemobrainfog 14,391,343
	@danafarber 12,730,838
	@brodalumab 12,520,907

 Tweet 228

## The Numbers

818,684,625 Impressions

205,685 Tweets

24,785 Participants

11 Avg Tweets/Hour

8 Avg Tweets/Participant

 Tweet 0

# Healthcare Hashtag Project symplur.com

The screenshot shows the Symplur website interface for the Healthcare Hashtag Project. At the top, there is a navigation bar with the Symplur logo, menu items for SYMPLUR SIGNALS, HEALTHCARE HASHTAGS (with a dropdown arrow), BLOG, and CONTACT, and a search bar labeled 'Search Symplur'. Below the navigation bar is a horizontal menu with six categories: Healthcare Hashtags (highlighted in orange), Tweet Chats, Conferences, Diseases, Ontologies, and Regular. The main content area is split into two columns. The left column is titled 'Why the Healthcare Hashtag Project?' and contains three bullet points: 'Discover Where The Healthcare Conversations Are Taking Place', 'Discover Who To Follow Within Your Specialty Or Disease', and 'Discover What Healthcare Topics Are Trending In Real-Time'. Below these points is a search bar with the placeholder text 'Search Symplur' and a magnifying glass icon. The right column is titled 'The Community by the Numbers' and displays four statistics: '1,104,087,577 Tweets' (with an orange 'Tweets' tag), '15,396 Topics' (with a green 'Topics' tag), '8,054 Hashtags' (with a yellow 'Hashtags' tag), and '3,112 Contributors' (with a blue 'Contributors' tag). Below the main content area, there are four columns, each representing a category: Tweet Chats, Conferences, Diseases, and Regular. Each column has a 'TRENDING' section with a list of three hashtags. For Tweet Chats, the trending hashtags are #MedX, #BCSM, and #AHealthierNation. For Conferences, they are #medx, #AHIMACon15, and #CIMCon15. For Diseases, they are #Migraine, #CRPS, and #Lymphoma. For Regular, they are #FOAMed, #FFpaciente, and #ZeroSuicide.

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SYMPLUR SIGNALS HEALTHCARE HASHTAGS ▾ BLOG CONTACT Search Symplur

Healthcare Hashtags Tweet Chats Conferences Diseases Ontologies Regular

### Why the Healthcare Hashtag Project?

Discover Where The Healthcare Conversations Are Taking Place

Discover Who To Follow Within Your Specialty Or Disease

Discover What Healthcare Topics Are Trending In Real-Time

Search Symplur

### The Community by the Numbers

1,104,087,577 **Tweets**

15,396 **Topics**

8,054 **Hashtags**

3,112 **Contributors**

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### Tweet Chats

TRENDING

1. #MedX
2. #BCSM
3. #AHealthierNation

### Conferences

TRENDING

1. #medx
2. #AHIMACon15
3. #CIMCon15

### Diseases

TRENDING

1. #Migraine
2. #CRPS
3. #Lymphoma

### Regular

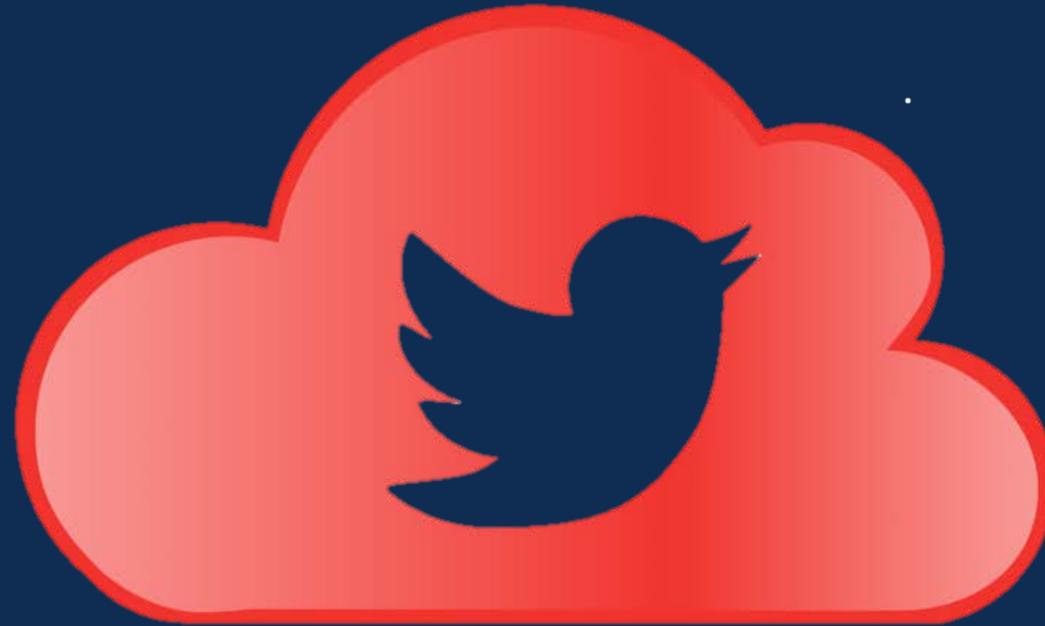
TRENDING

1. #FOAMed
2. #FFpaciente
3. #ZeroSuicide

# Conferences & Research

# Conference Tweeting

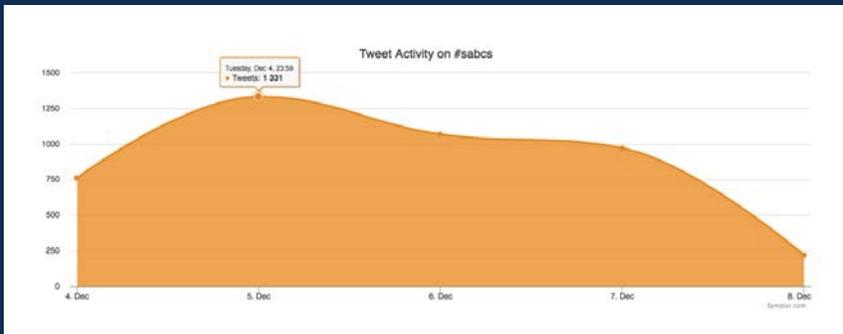
WHY?



HOW?

# Why Tweet about Key Events?

- Increase size of audience
- No geographical limits
- No Financial barriers
- Amplify information being presented
- Potential to grow support base



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Home / Healthcare Hashtags / #sabcs / Analytics

### The #sabcs Influencers

#### Top 10 by Mentions

- @drsteventucker 359
- @chemobrainfog 282
- AACR @aacr 261
- @regrounding 225
- @jodyms 202
- @karunajaggar 168
- @teamoncology 166
- @bcaction 116
- @BRSTKNKRactie 72
- @jrgralow 70

#### Top 10 by Tweets

- @regrounding 323
- @chemobrainfog 274
- @drsteventucker 214
- @teamoncology 209
- @thecancergeek 148
- @bcaction 107
- @karunajaggar 103
- @onclive 79
- @jrgralow 79
- @itsthebunk 72

#### Top 10 by Impressions

- @susangkomen 2,158,268
- @teamoncology 1,567,500
- @drsteventucker 1,331,294
- @bcaction 1,305,293
- @chemobrainfog 1,214,916
- @roche 1,076,850
- @novartis 860,368
- @regrounding 841,415
- @drseisenberg 531,512
- @oncologytimes 524,250

### The Numbers

18,894,472 Impressions

4,349 Tweets

670 Participants

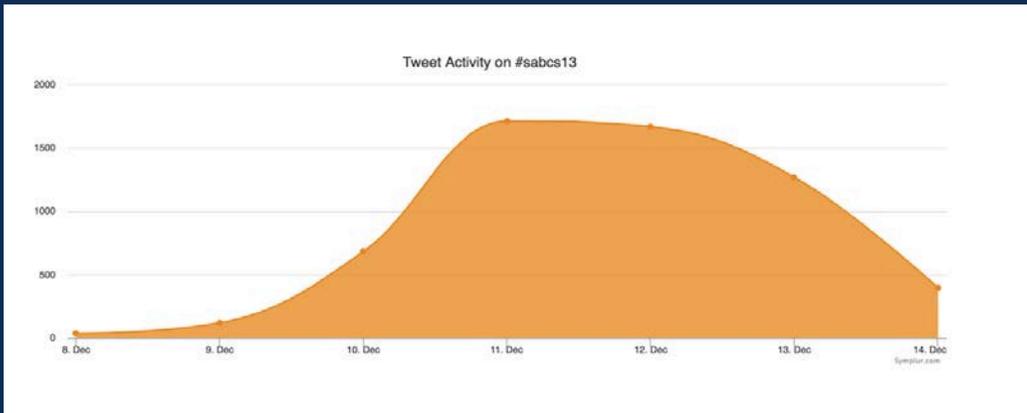
36 Avg Tweets/Hour

6 Avg Tweets/Participant

[Tweet](#) [Like](#)

#sabcs analytics for time period 12/04/2012 00:00 to 12/08/2012 23:59 (Pacific Time: GMT-0700) [\[change time period\]](#)

# 2012



Home / Healthcare Hashtags / #sabcs13 / Analytics

### The #sabcs13 Influencers

#### Top 10 by Mentions

- @rsm2800 332
- @teamoncology 317
- @thecancergeek 297
- @jrgralow 247
- @chemobrainfog 222
- JNCI @jnci\_now 183
- @karunajaggar 165
- @roche 138
- @susangkomen 130
- AACR @aacr 120

#### Top 10 by Tweets

- @thecancergeek 381
- @rsm2800 260
- @teamoncology 192
- @talkibc 192
- @chemobrainfog 172
- @drmisialek 155
- @jrgralow 123
- @ragna\_sabcs13 114
- @caseofdees 113
- @karunajaggar 86

#### Top 10 by Impressions

- @rsm2800 1,391,260
- @thecancergeek 795,147
- @talkabouthealth 228,514
- @lizszabo 106,770
- @talkibc 80,448
- @dianeradfordmd 56,540
- @ascopost 53,358
- @karunajaggar 38,958
- @dramarivirg 24,605
- @luriecancer 22,875

#### The Numbers

- 2,926,452 Impressions
- 5,886 Tweets
- 1,016 Participants
- 35 Avg Tweets/Hour
- 6 Avg Tweets/Participant

[Tweet](#) [Like](#)

#sabcs13 analytics for time period 12/08/2013 00:00 to 12/15/2013 00:00 (Pacific Time: GMT-0700) [\[change time period\]](#)

# 2013

# HOW?

Register the conference hashtag!!

<http://www.symplur.com/healthcare-hashtags/>

Healthcare Conferences



The People Behind Symplur

Howard J Luks, M.D.

Audun Utengen, MBA

The Fox Group, LLC

# Healthcare Conferences

## Healthcare Conferences

Featured Healthcare Conferences

Sep 16 2016 Live [#medx](#) [Stanford Medicine X 2016](#)

All Healthcare Conferences & Events

Sep 12 2016	<a href="#">#wmcsp16</a>	<a href="#">West Midlands CSP study day 2016</a>
Sep 12 2016	<a href="#">#EASD2016</a>	<a href="#">52nd European Association For The Study Of Diabetes Annual Meeting 2016</a>
Sep 12 2016	<a href="#">#MNDCnf16</a>	<a href="#">8th National Motor Neurone Disease Conference</a>
Sep 12 2016	<a href="#">#NACCT16</a>	<a href="#">North American Congress of Clinical Toxicology</a>
Sep 12 2016	<span>Live</span> <a href="#">#MayoClinicFL</a>	<a href="#">Twitter Wars at Mayo Clinic in Florida</a>
Sep 12 2016	<a href="#">#CMIMI</a>	<a href="#">SIIM Scientific Conference on Machine Intelligence in Medical Imaging</a>
Sep 12 2016	<a href="#">#DIALabeling16</a>	<a href="#">DIA Global Labeling Conference 2016</a>
Sep 12 2016	<a href="#">#PPFEd16</a>	<a href="#">Past Present Future of Medicine</a>
Sep 12 2016	<a href="#">#concordium16</a>	<a href="#">Concordium</a>
Sep 12 2016	<a href="#">#TForm2016</a>	<a href="#">Transformathon</a>
Sep 12 2016	<a href="#">#HCEG16</a>	<a href="#">Healthcare Executive Group Annual Forum 2016</a>
Sep 12 2016	<a href="#">#PopHealthIT</a>	<a href="#">HIMSS Pop Health Forum 2016</a>
Sep 12 2016	<a href="#">#DIALabeling2016</a>	<a href="#">Global Labeling 2016</a>

110,983 Conf. Tweets  
20,439 Conf. Participants

Real-time Analytics: Last 7 days

### Trending

1. [#EASD2016](#)
2. [#APACForum](#)
3. [#medx](#)
4. [#ECTRIMS2016](#)
5. [#STTILC16](#)
6. [#ACCLegConf](#)
7. [#DHC14](#)
8. [#SHSMD16](#)
9. [#BackPainDay2016](#)
10. [#NICFall2016](#)
11. [#CMIMI](#)
12. [#VIVA16](#)
13. [#IETAHL](#)
14. [#AAST2016](#)
15. [#NPNR2016](#)

## #MayoClinicFL Conference Hashtag

Twitter Wars at Mayo Clinic in Florida

Monday 12th September 2016 - Wednesday 28th September 2016

Staff engagement campaign for employees at Mayo Clinic in Florida, September 12 -28, 2016. Twitter Wars, a Twitter competition, brings friendly competition and unity, while empowering employees to "get social."

#MayoClinicFL is a healthcare conference hashtag submitted by @AudreyLaine2

## What is #MayoClinicFL?

Healthcare Topics

- [healthcare social media](#)

Related Hashtags

- [#GT2015](#)
- [#SEMES2015](#)
- [#clinicaethics](#)
- [#JPM16](#)
- [#saudihealth](#)

[Tweet](#)

# BEFORE THE CONFERENCE

- Generate pre-conference buzz
- Identify key persons not in attendance to follow hashtag
- Prepare a twitter list of people to follow
- Locate twitter handles of scheduled speakers

# AT THE CONFERENCE

- Identify source of information in your tweets
- List twitter handles of scheduled speakers
- Post photos at venue in tweets
- When permitted, include photos of slides from sessions
- Watch the hashtag, share what others are tweeting

# SHARING RESEARCH FINDINGS

- Find appropriate Facebook groups to share relevant research
- Write an introduction for Facebook posts
- Use twitter to target interested communities. Hashtag it!

# DO'S AND DON'T'S FOR SHARING

- Do NOT sensationalize
- Check before sharing what other's may have posted
- If not using retweet or share feature, give credit
- Distinguish between initial presentation & peer reviewed, published
- Be clear – is it basic science or translational research
- Don't be afraid to question over-hyped information
- Do your homework

# BUILD AND PROTECT YOUR REPUTATION

- Be respectful
- Be social
- Collaborate
- Ask others for input
- Everything you post, is there forever.
- Don't be hasty with the "enter" button!

# Policy/Legislative Advocacy

- Hill Day
- Remote Participation
- Legislative Support



From: politico.com

# Hill Day: Overview

Hill Days are usually coordinated visits for advocates to meet personally with a member of Congress or their staff to advocate for particular legislation or general support for topics that concern the organizing group.

- Legislative Briefing
- Assigned Teams & Prearranged Appointments
- Background Materials
- Lead Advocate

# Hill Day: Before You GO

- BEFORE YOU GO:
  - Follow MCs before visit:  
<https://twitter.com/cspan/lists/members-of-congress?lang=en>
  - Identify advocates in the district– even if they aren't going
  - Recruit colleagues to participate by retweeting
  - Tweet before your visit – make a clear "ask"

# Hill Day: On The Hill

- ON THE HILL:
  - Record any commitments made or concerns expressed
  - Mention and tweet to constituents
  - Take photo with staff
  - THANK THEM!



**Lori Marx-Rubiner**  
@regrounding

Thanks to @RepChuck for sharing your relationship to cancer. #RealHopels seeing my son grow up Thx for ur support! @AACR @ASCO @AACI\_Cancer

# Hill Day: After You Visit

- AFTER VISIT:

- Send TY tweet ASAP

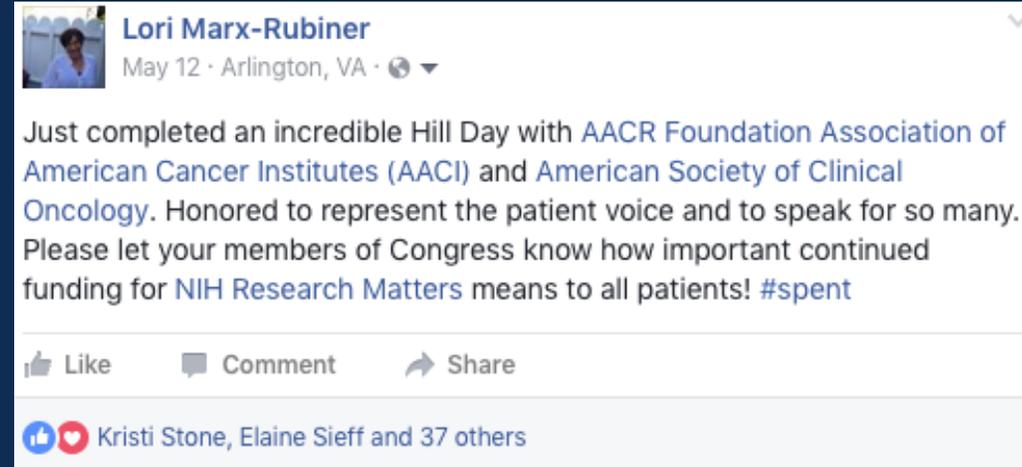
- Include any “public” statements you can share

- ALWAYS find something positive to keep the conversation rolling

- Continue to follow the MC – watch for news on your subject

- Use Facebook and blogs to summarize event, positions taken

- Include links to MCs and suggestions for follow up



# Hill Day: Targeting Your Message

- TARGETING YOUR MESSAGE:
  - USE HASHTAGS – Choose from among:
    - Be consistent – groups should identify 2-3 tags (ideally short!) and use them
    - #LegislationTag    #DiseaseName  
#RelevantCommunity
  - DIRECT YOUR TWEETS:
    - @MemberOfCongress    @GroupName

# Remote Participation

- BEFORE HILL DAY:
  - Get briefing materials if possible
  - Follow MCs before visit
  - Identify and follow advocate visiting YOUR representatives
  - Arrange to follow relevant hashtags
- ON HILL DAY:
  - Especially important to watch your representative's feed
  - Retweet what you can

# Remote Participation

- AFTER VISIT:
  - Personally contact staffer from initial meetings
  - Continue to follow the MC – watch for news on your subject
  - Tweet again as legislation deadline gets closer
  - Post summaries of event on Facebook and share the posts of others
  - Use the tags identified by the organizers
    - #LegislationTag #DiseaseName #RelevantCommunity
  - Direct your tweets
    - @MemberOfCongress @GroupName

# Legislative Support

- FOLLOW:
  - Confirm bill number(s) and follow any hashtags
  - Follow on GovTrack.US
- CONNECT:
  - Identify and coordinate with like-minded communities
  - Share information quickly with followers using hashtags
  - Updated content keeps people interested
  - ASK for retweets or like/shared on Facebook
  - Explain your positions

# Thank You!

