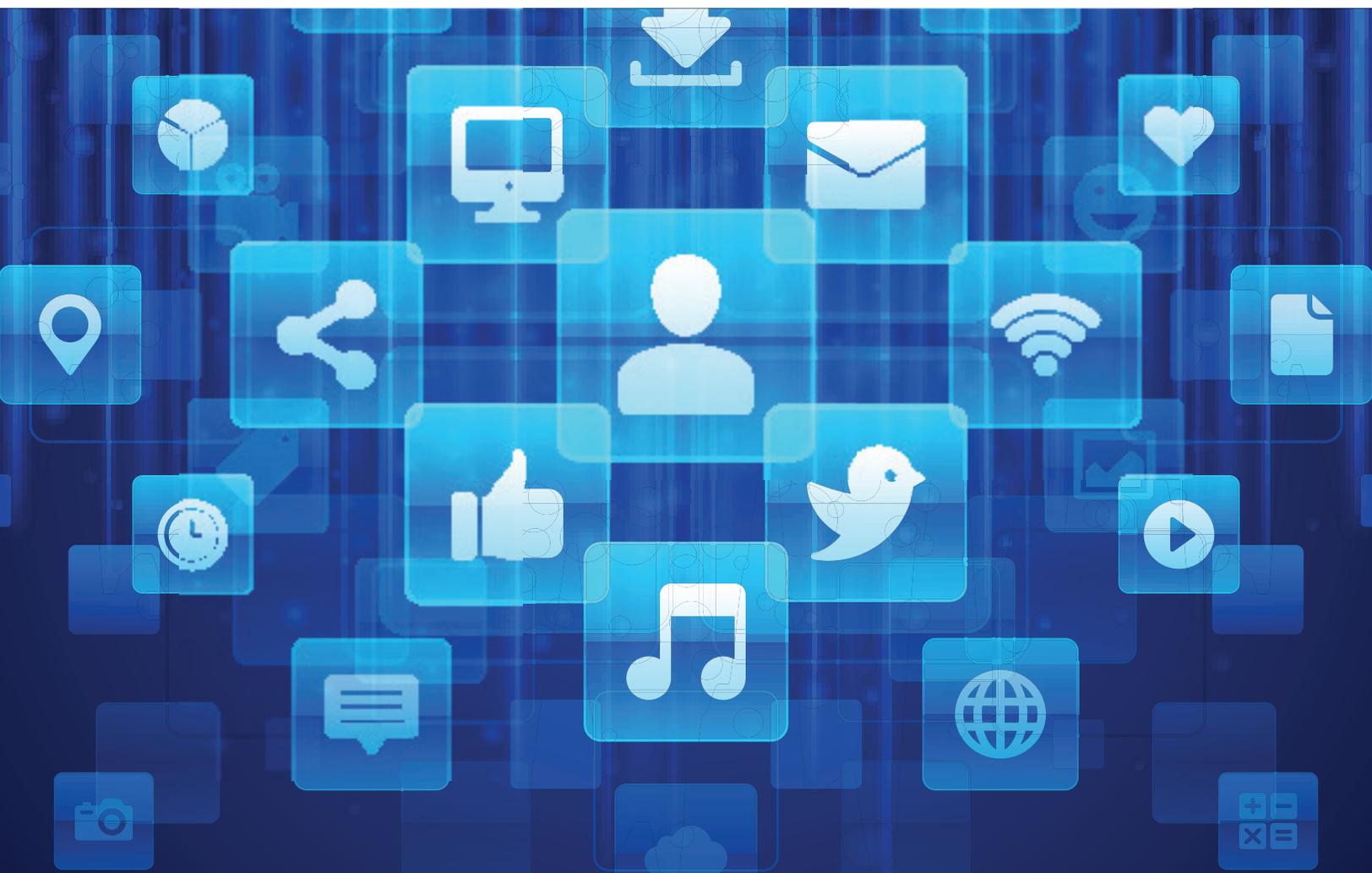


# Digital Health Advocacy (#dhAdv) Summit 2014

## RESOURCE GUIDE



**#dhAdvocacy SUMMIT**



digital health advocacy  
in a digital world



GLOBAL HEALTHY LIVING  
FOUNDATION

## Introduction: Message from Seth Ginsberg

Dear Colleague:

On behalf of the Global Healthy Living Foundation, welcome to the 2014 Digital Health Advocacy Summit – The Objective Digital Health Advocacy Voice.

#dhAdv

Whether you're returning for the fourth year, or this is your first time joining us, we're glad you're here. We have assembled the pioneers in the field of social media and advocacy, whose lessons and insights will live on well after today's interactive discussion (videos will be posted on [www.dhAdvocacy.org](http://www.dhAdvocacy.org)).

#dhAdv

Digital Health Advocacy means using social media to advance our collective advocacy and policy priorities. It's GHLF's brand of nurtured collaborative advocacy. It's the opportunity to brush up on mechanics, to borrow best practices, to share experiences and to motivate each other to continue pushing boundaries and to leverage new media tools to support our missions.

#dhAdv

America's healthcare environment is rapidly changing, and our organizations must remain ahead of that change and be the stewards of that change - so that together, we can improve access to care and the health outcomes of our country. We're glad you've joined us.

#dhAdv

To Success,



Seth D. Ginsberg  
Co-Founder,  
Global Healthy Living Foundation  
@GHLForg

# dhAdvocacy: Agenda

Time	Session	Speaker
8:00 AM EST	<b>Breakfast Workshop: Social Media 101</b>	Amanda Phraner – Vice President Digital Health, Edelman @aphraner
9:00 AM EST	<b>Breakfast/Networking</b>	
9:30 AM EST	<b>Main Program: Welcoming Remarks</b>	Seth Ginsberg – President, GHLF @GHLForg @CreakyJoints
10:00 AM EST	<b>Let's "Like" Research</b>	Cecilia Arradaza – Managing Director Communication & Policy FasterCures @carradaza  Paul Bove – Social Media Lead U.S. Food and Drug Administration @paulfbove
10:45 AM EST	<b>Capitol Communication: What's Most Effective?</b>	Michael Ricci – Deputy Communication Director  Speaker John Boehner @riccimike
11:15 AM EST	<b>Social Media Analytics: Do You Know your Numbers?</b>	Cody Damon – President Media Cause @codydamon
12:00 PM EST	<b>Lunch/Networking</b>	
12:40 PM EST	<b>Keynote: You Say You Want a Revolution...</b>	Marvin Ammori @ammori
1:45 – 2:00 PM EST	<b>Closing Remarks</b>	Seth Ginsberg – President, GHLF @GHLForg @CreakyJoints

# dhAdvocacy: Speakers Bios

## AMANDA PHRANER

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Vice President  
Digital Health, Edelman  
@aphraner



Amanda Phraner is a Vice President of digital health at Edelman where she brings nearly a decade of public affairs and online engagement experience to help clients leverage digital technologies and effectively communicate with their target audiences. At Edelman, Amanda develops digital communications plans to educate consumers on important health and safety issues, leads content strategy to engage audiences to disseminate important resources among their networks, and manages the creation of interactive content that helps to drive action.

Prior to joining Edelman, Amanda oversaw community engagement and issue advocacy campaigns to help build a base of support for clients including the American Medical Associations' Patient Action Network.

She studied marketing and political science as an undergraduate at Lindenwood University. In addition, Amanda completed her M.A. in Political Management from The George Washington University.

## SETH GINSBERG

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President  
GHLF  
@GHLForg @CreakyJoints



Seth Ginsberg is America's Health Advocate, and a thought leader in the global health innovation and access-to-care conversation for the past 15 years. Ginsberg was diagnosed at age 13 with Spondylarthritis, and, at 18, he pioneered the world's first Online Patient Community for the millions of people worldwide suffering from arthritis, called CreakyJoints (<http://www.CreakyJoints.org>).

Today, CreakyJoints sustains thousands of engagements a day through its social media channels, serving as a model for interactive delivery of patient education, support services, advocacy efforts and patient-centered research. CreakyJoints is the flagship of its parent Global Healthy Living Foundation (GHLF), a New York-based 501(c)(3) non-profit organization, co-founded by Ginsberg and entrepreneur Louis Tharp in 1999.

## CECILIA ARRADAZA

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Managing Director  
Communication & Policy FasterCures  
@carradaza



Cecilia Arradaza is FasterCures' managing director of communications and policy. She manages the organization's communications programs, stakeholder outreach strategies, and policy priorities. Arradaza brings to FasterCures more than 15 years of experience in strategic communications on key issues that impact medical research and the life sciences industry. She joined FasterCures from Chandler Chicco Agency (CCA), a health communications firm, where she managed public affairs programs for clients including Johnson & Johnson, the Robert Wood Johnson Foundation, and VHA Inc. Before joining CCA, Arradaza implemented issues advocacy initiatives for pharmaceutical and foundation clients of Hyde Park Communications, managed media relations and public education efforts for the American Psychiatric Association, and was part of the health and international public affairs practices at Powell Tate. Arradaza began her health communications career at the National Osteoporosis Foundation and the National Women's Health Network. She is on the founding board of Women Against Alzheimer's. She received her bachelor's degree from George Washington University at Mount Vernon College.

## PAUL F. BOVE

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Social Media Lead  
U.S. Food and Drug Administration  
@paulfbove



Paul is the Social Media Lead for the U.S. Food and Drug Administration, managing FDA's social media program. Before coming to FDA, he was a government contractor with RMCI, serving as the Social Media Manager for the CIO Web Team at the U.S. Office of Personnel Management. Prior to this position, he was the Social Media Strategist and Senior Web Developer within the Air Force Public Affairs Agency, helping build one of the Department of Defense's first social media and emerging technology teams. With a strong focus and specialization on internal policy and education, Paul brings over a decade of communications experience from the government and non-profit world. Additionally, he is an Adjunct Professor of Public Communication at American University, teaching Social Media Strategy and Tactics.

Paul has experience with print media, crisis communications, Web development, digital communications, and technical writing. Paul completed his Master's in Public Relations and Corporate Communications from Georgetown University, with a focus on digital media and strategy. He also co-authored "New Media and the Air Force," a primer on new and social media, and worked on the companion video of the same name.

# dhAdvocacy: Speakers Bios

## MICHAEL RICCI

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Deputy Communication Director  
Speaker John Boehner  
@riccimike



Now in his tenth year on Capitol Hill, Michael Ricci serves as Deputy Communications Director for the Office of House Speaker John Boehner, where he oversees the creation of all written and digital content. That includes speeches, letters, press releases, blog posts, talking points, tweets, Facebook posts, graphics, and videos. Prior to joining Boehner's office, Michael served as Deputy Communications Director for the House Republican Conference and Speechwriter for the National Republican Congressional Committee. Michael grew up in East Meadow, NY and attended Columbia University. You can follow him on Twitter at riccimike or Instagram at ricciruns.

## CODY DAMON

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President  
Media Cause  
@codydamon



Cody is passionate about the role digital technologies play in helping non-profits compete for attention. He is proficient across the whole gambit of social platforms and digital advertising networks, but his true strength lies in the coordination of all of these channels to form an effective communication strategy for his clients. Cody's ideas have spawned actionable change for partners such as (RED), NRDC, and the Cornell Lab of Ornithology.

## MARVIN AMMORI

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@ammori



Mr. Ammori is a thought leader in Internet law, best known for his work opposing SOPA (Stop Online Piracy Act) and defending network neutrality. Time Magazine calls him “a prominent First Amendment lawyer and Internet policy expert” and the San Jose Mercury describes him as “a well-known advocate for Internet freedom.” Mr. Ammori is one of the leaders of a diverse coalition of businesses and advocacy organizations whose digital campaign around network neutrality resulted in the crashing of the FCC’s public comment portal after a record 3 million submissions were received. Mr. Ammori authored an article in Slate capturing the arguments that led to this massive outpouring of support.

Additionally, he serves on the boards of the nonprofit advocacy groups Fight for the Future and Demand Progress and also on the Board of Engine Advocacy, a national organization that gives startups a voice in DC. In private practice, he has represented several companies and coalitions including Google, Dropbox, eBay, Automattic, Tumblr, Twitter, and others.

Mr. Ammori authored the book *On Internet Freedom*. His law review articles exploring First Amendment theory, have been published in the Harvard Law Review, Wisconsin Law Review, and Foreign Affairs.

## JAN FOX

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Web Stream Moderator  
Fox Talks  
@JanFoxTalks



If you’d lived in the DC Metro area, you’d recognize JAN FOX right away. She was a 4-Time Emmy Winning journalist at CBS WUSA 9 for almost 20 years! Before that... a Talk Show Host on ABC in Boston and the 6 & 11 PM Anchor on NBC in Portland, ME.

For life after TV, Jan put up the shingle— Fox Talks – teaching you, 100’s of audiences, and her coaching clients to “Sharpen Your SPEAKability”. Her book, “GET YOURSELF on TV”, gives you INSider secrets to get INSide the studio. She’s on the board of the National Speakers Association DC chapter. Jan has a Masters of Education in Humanistic Studies, but the way the world looks at anything has changed since then. Little known fact – She sent something LIVE in a box that snagged the Channel 9 job. You’ll have to ask her!

# Resources: Social Media Training and Tone from Edelman

## NORTH STAR: WHAT IS YOUR GOAL?

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Your “North Star” should be the primary goal/mission statement that guides all actions and strategies on social media. This will provide guardrails to the online content creation process and help you decide what is and isn’t helping you achieve your goals. – **Do you have a north Star?**

## HOW TO CREATE VALUE-FIVE C'S OF COMMUNITY TO THE "THE FIVE C'S OF COMMUNITY"

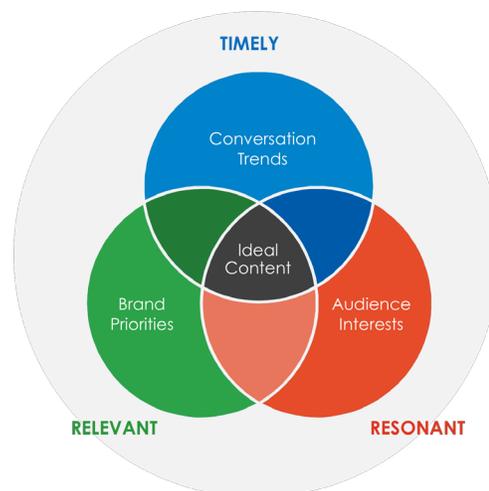
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To create a lifetime value within a community, adhere to the “The Five C’s of Community”:

- » **Content:** Value provided through quality content that educates, inspires, informs and connects community members.
- » **Context:** Value provided by deep understanding of how participants within the community want to engage and the tools they use to do so.
- » **Connectivity:** Value provided by connecting members of community in mutually beneficial ways.
- » **Continuity:** Value provided by sustaining efforts over time, ensuring that community is healthy and productive.
- » **Collaboration:** Value established through collaborative efforts of participants who share, co-create, and edit each other’s efforts.

## NORTH STAR: WHAT IS YOUR GOAL?

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## BEST PRACTICES: SOCIAL MEDIA USAGE OVERVIEW

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- » **Short is sweet:** Some say the ideal tweet is 100 characters, others say the ideal Facebook post is 40 words or less... basically less is more.
- » **Cross-promote your social media accounts:** This is one of the best ways to grow your fan base with targeted followers.
- » **Incorporate images into your social strategy:** For example, on Twitter, they receive 150% more retweets.
- » **Try posting to social media 'after hours':** Some businesses have reported that their highest engagement levels occur in the early morning or late at night. Imagine this would apply to college students as well!

## BEST PRACTICES: TONE AND VOICE OVERVIEW

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- » **Be conversational:** This is social media, not an advertisement.
- » **Use a consistent voice on all platforms:** Consciously decide what you want your social media voice to be: Casual? Funny? Corporate?
- » **Engage with others:** Participate in other people's social media conversations, rather than always starting your own.
- » **Be a listener:** Focus on what your followers need to hear, rather than on what you feel you need to tell them.
- » **Ask for help:** Engage your social media followers for help; they'll love to offer suggestions on ideas or give honest feedback.

## BEST PRACTICES: TWITTER

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### **Ideal length of a tweet is approx. 100 characters**

- » This keeps tweets short enough that others can retweet them and have enough space to engage with their own opinion/reaction.
- » Use links within your tweets for the best chance of getting retweeted. Increases web traffic, too.

### **Live-Tweeting**

- » PROS: Share information with those that can't be there; make online connections
- » CAVEATS: Don't do it for the sake of doing it; must prepare for multiple outcomes; don't forget to listen

## BEST PRACTICES: FACEBOOK

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### **The ideal length of a Facebook post is less than 40 characters**

- » This is ultra short! And often not achievable with what you need to say.
- » Additional Facebook-length analyses say 80 characters is the ideal length of a post and that posts with 80 or fewer received 66 percent higher engagement.

## BEST PRACTICES: INSTAGRAM

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- » Ask your Instagram followers to share photos of themselves. This could work for photos of students on campus, and then vote for the best picture.
- » When using Instagram, try using one of the 3 most effective filters: Normal, Mayfair or Inkwel.

## BEST PRACTICES: PINTEREST

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- » Use vertically-oriented images: They tend to outperform horizontally-oriented ones.
- » Avoid using human faces in your photos: Images without faces get shared more often.

## Resource: Analytics Info

<http://www.MediaCause.org>

## Resource: Blogger Codes / Helpful Links to Partners/ Friends

**Creaky Joints applies the New York Times code of journalism ethics for its correspondents who are journalists**

<http://www.nytco.com/who-we-are/culture/standards-and-ethics/>

**Patient bloggers write personal narratives, not journalistic pieces, though there is a lot of debate over whether journalistic standards should apply to bloggers**

<http://fromtheleft.wordpress.com/bloggers-code-of-ethics/>



# Facebook Petition Information

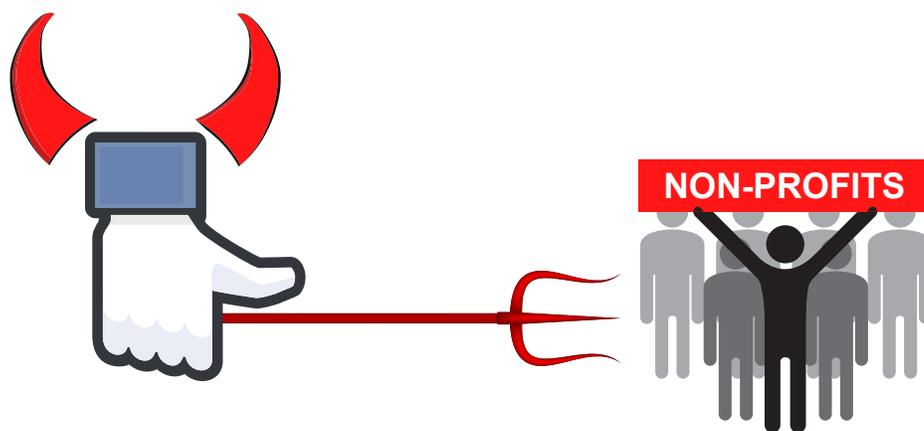
## Keep Facebook Free For Non-Profits

GHLF has been spearheading a petition on Change.org which has already received 17,500+ signatures, asking Facebook to either change its algorithm for non-profits, or otherwise accommodate non-profits with a solution (such as an ad-grant program similar to Google's). As you may know, the social network changed its algorithm to limit "organic reach" — the number of Facebook users who can potentially see any single piece of content in their newsfeed — the move was characterized as a way for the company to extract additional advertising revenue from corporate brands. The consequences, however, will be felt much more acutely by the many nonprofit organizations now subject to the same reduction in reach — reportedly down to only 1 or 2 percent of all followers. A nonprofit advocacy group with 5,000 followers, for example, might issue a critical call to action that is only seen by 50 of its followers.

Thousands of non-profits, without much money, had dramatically improved their reach into world-wide communities, improving the environment, human rights, medical care, economic conditions and other critical issues that determine society's quality-of-life. Non-profits have been caught in Facebook's policy change, which has severely limited our reach unless we pay to promote our posts, as for-profit corporations do.

GHLF's co-founder Seth Ginsberg authored an op-ed that ran in two dozen markets throughout the country. Nonprofit Quarterly joined in supporting the effort with its recent editorial endorsing non-profits' fight against Facebook.

Now it's your chance to join the initiative! Tell Facebook to change it's algorithm for non-profit organizations so that everyone can get the help that they need. We look forward to discussing this #dhAdv issue with you and more in person at the 2014 dhAdvocacy Summit.



# Thank you to our Sponsors



wishes to thank our sponsors for their support of the 2014 Digital Health Advocacy Summit (logo):

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Supporting Sponsor:



Digital Health Advocacy, or dhAdvocacy, will use @dhAdvocacy as its Twitter handle, and #dhAdv. The website will be [www.dhAdvocacy.org](http://www.dhAdvocacy.org)



**Global Healthy Living Foundation**

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

For more informaion please contact Steve Marmaras at [smarmaras@ghlf.org](mailto:smarmaras@ghlf.org) or (203) 470-9309

**#dhAdvocacy SUMMIT**



digital health advocacy  
in a digital world