

## Drugs in the Media: Diseases, Doctors, and Social Media

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UNIVERSITY OF UTAH  
HEALTH CARE



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## Disclosures

- INSPPIRE to Study Acute Recurrent and Chronic Pancreatitis in Children, Grant # 10987759, National Institutes of Health (NIH), National Institute of Diabetes and Digestive and Kidney Diseases
- Speaker's bureau for Medical Education Resources, Inc.

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## Goals and Objectives

- Understand where online information comes from which can promote possible controversies about disease processes and medication use in our patients.
- Understand good approaches to addressing online sources of information with patients and their families.
- Understand how to provide accurate on-line medical resources to our patients and their families.

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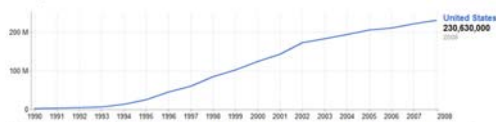
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## The World is Becoming More Connected

### Internet users

People with access to the Internet.



Data source: World Bank, World Development Indicators - Last updated Mar 29, 2011

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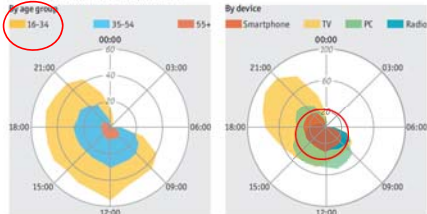
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## The World is Becoming More Connected

### Smartphone use

% reporting use by hour of the day, over a week\*



**Two billion** smart phones in use worldwide.

By 2020, **80% of world adults** will have access to a smartphone and the Internet.

*The Economist, February 26, 2015*

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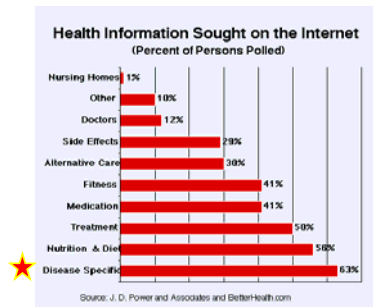
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## What are Patients Doing on the Internet?



National Center for Policy Analysis

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## What are Patients Doing on the Internet?

Survey of IBD patients at the Mayo Clinic:

- 59% obtained information from their gastroenterologist; 54% from the internet.
- Most patients who used the Internet were < 40 years old.
- Significantly *more* Internet use seen with education level, *not* income.
- 57% thought Internet info was **trustworthy / very trustworthy**.

Cima P, et al. Inflamm Bowel Dis. 2007; 13: 1266-1270.

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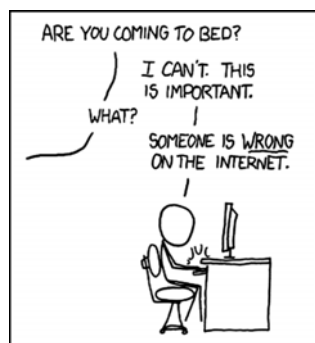
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### What are Patients Doing on the Internet?

Quality indicator study of colic web sites:

- Study looked at 24 internet sites for **colic**-specific content.
- *Only one third of sites* included information on parental stress and risk of infant abuse from colic.
- Recommended that practitioners should “guide parents to reliable colic resources.”

Bailey S, et al. J Pediatr Health Care. 2013; 27: 443-450.

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### What are Patients Doing on the Internet?

Study of search term “celiac disease” and association with accuracy of medical information:

- 100 top celiac websites (Google, Bing, Yahoo!) were selected.
- 3 reviewers looked at sites to determine **minimum** presence of helpful information (symptoms, testing, diet, etc.).
- Only 4 sites achieved a minimal score for accuracy, reading comprehension, and transparency. Academic websites has significantly less transparency.

McNally S, et al. Interact J Med Res. 2012; 1: e1

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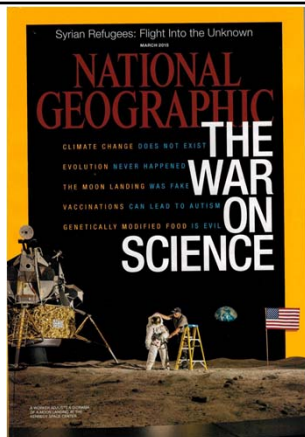
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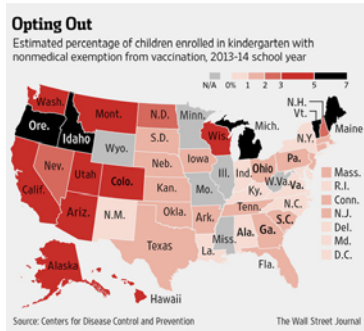
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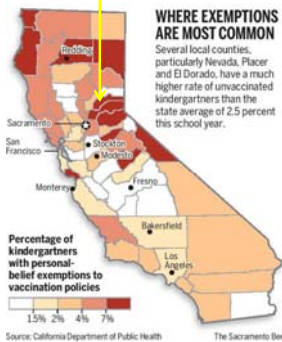
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## Vaccination Exemption Rates by State



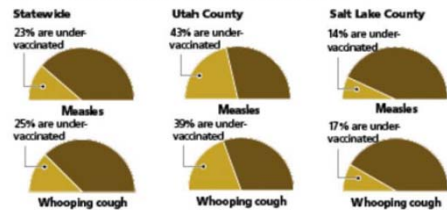
Wall Street Journal

### Nevada County 21% exemption rate



"The lowest vaccination rates tend to be in rural and wealthy parts..."  
-Sacramento Bee

**Herd immunity** - The CDC says at least 92 percent of a group must have the measles (MMR) or whooping cough (DTaP) vaccine to reach herd immunity. Here is a look at the percentage of schools where the kindergarten population fell below that threshold.



A parent may claim an exemption to immunization for medical, religious, or personal reasons, as allowed by Section 53A-11-302 of the **Utah Statutory Code**.

### From BMJ "Practice: A Patient's Journey"

- "Then followed two decades of unexplained ill health...including weakness, exhaustion, bloating, nausea, indigestion, diarrhoea, skin rashes, ingrown hairs, cracked skin, joint and muscle pain, anal leakage of undigested fat, oscillating body weight, numbness in my feet and hands, muscle spasms in my legs (especially at night), mood swings, mild depression, and disturbed sleep patterns.
- "Medical professionals seemed mystified or dismissive and had no explanation. [A] ...young consultant told me that people with symptoms like mine often commit suicide."
- "I went to see the consultant who had carried out the gall bladder operation and excitedly told him about my discovery that gluten and lactose were the source of all my health problems... He seemed quite uninterested but told me to carry on with the gluten and lactose exclusion diet "if you find it is working for you."

Published in BMJ (2012) as description of gluten sensitivity.

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**Are We Listening to Our Patients?**

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### What is out there on the Web?

- Fecal transplant "Do It At Home!"
- "Fecal Transplant At Home – DIY Instructions"  
Based on the **experiences of one person**, the **anecdotal reports of others** and questions most frequently asked by e-Patients.
- **Website states it is not providing medical advice.**

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## What is out there on the Web?

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## What is out there on the Web?

Fecal transplant success claimed for:

- Ulcerative colitis
- Crohn disease
- *C. difficile*
- Multiple sclerosis
- IBS (diarrhea type)
- Constipation
- Food intolerance
- Chronic fatigue syndrome
- "Recovery from a-whole-lot-of-awful-stuff"

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↑  
**NOT AN ICD-10 CODE!**

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## What is out there on the Web?

- Eosinophilic esophagitis: The “Natural” Approach
- One web site advocates for naturopathic care identifying food sensitivities and promoting the immune system. No info provided for how this is accomplished.
- At very bottom of web page:

*The advice provided in this article is for informational purposes only. It is meant to augment and not replace consultation with a licensed health care provider.*

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## What is out there on the Web?

- Credentials of EoE naturopath running website:
- “...fusion of the art and science of Naturopathic Medicine. The art is in recognizing the messages from the body – connecting the dots between seemingly unrelated symptoms... The science is in the use of natural medicines – dietary changes, stress-management techniques, nutritional supplements, botanical medicine, acupuncture.”
- Likes live music and hula hooping.



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What should be our approach in addressing this new source of information?

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What should be our approach in addressing this new source of information?



1. How do we address patient concerns based on internet sites?
2. How do we / should we engage in social media?

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How do we address patient concerns based on internet sites?

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#### How Should We Help our Patients On Line?

- Recognize that our patients/families are going to use on-line resources **regardless of our opinion!**
- Be willing to review website information provided by families.
- Be ready to provide website links that you think will be helpful.
- Keep in mind, in the end, many studies suggest **healthcare providers have the highest levels of trust when it comes to health care information.**

Cutilli. Ortho Nurs  
2010: 29: 214-219.

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#### How Should We Help our Patients On Line?

- Teach patients that ending designations of websites can help explain content
- .gov
- .edu
- .org (keeping in mind that anything can be an non-profit organization)
- .com

Tips from [www.kevinmd.com](http://www.kevinmd.com)  
"Help patients find information on the Internet: Tips to surf safely"

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#### How Should We Help our Patients On Line?

- Is the website legitimate?
- Does the physician / researcher have accreditation?
- Is the organization reputable / provide evidence of reputation?
- What kind of evidence is presented? (ex. "This medicine saved my life!!!!")
- Does the website have contact information?

Tips from [www.kevinmd.com](http://www.kevinmd.com)  
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How Do We  
Engage in Social Media?

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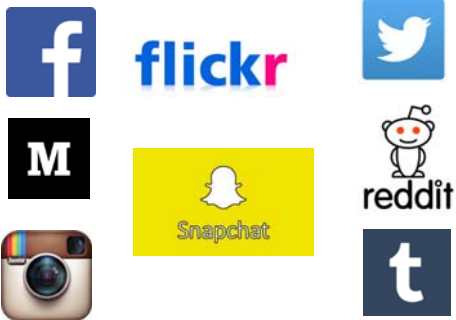
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What's Out There?



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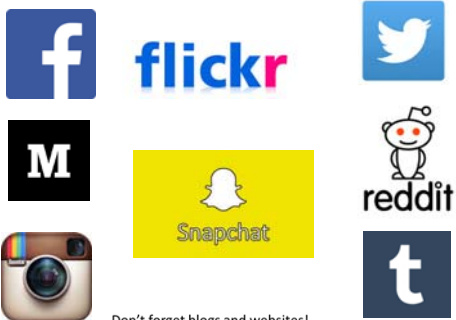
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What's Out There?



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## Why Should You Consider Social Media?

- Health advocacy and information for your patients / the public
- Medical education: Method to teach medical students, residents, fellows (ex: #FOAMed – Free Open Access Medical Education)
- Medical education: Way to keep up-to-date with medical news, use as a knowledge tool, etc. (ex: #meded)
- Networking (especially important in pediatric gastroenterology)
- Advertising? Market share? Research?

<http://wingofzock.org/2015/07/01/why-do-you-tweet-anyway-a-glance-into-meded-tweeting/>

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## My Personal Use of Social Media

- I have “personal” accounts for friends and family and “open” accounts for the public.
- I helped set up social media accounts for NASPGHAN and GIKids.org (now run by Innate -- <http://innateagency.com/>)
- I set up a Twitter feed for our GI division.

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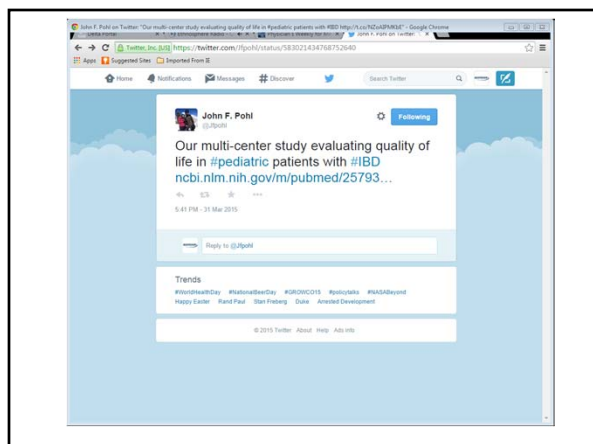
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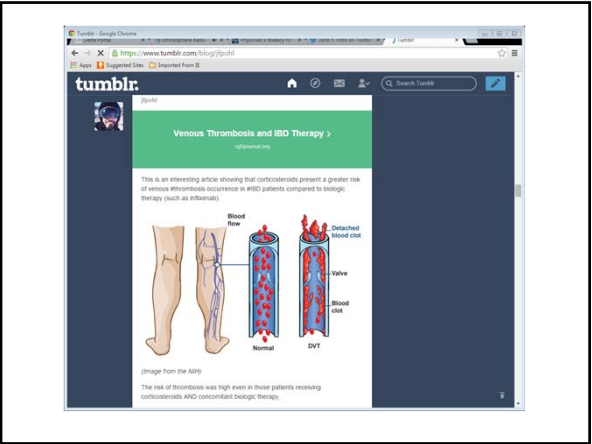
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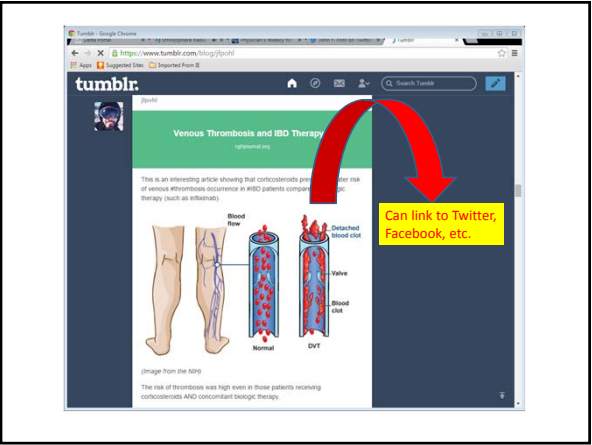
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## NASPGHAN Twitter Feed: Society Info




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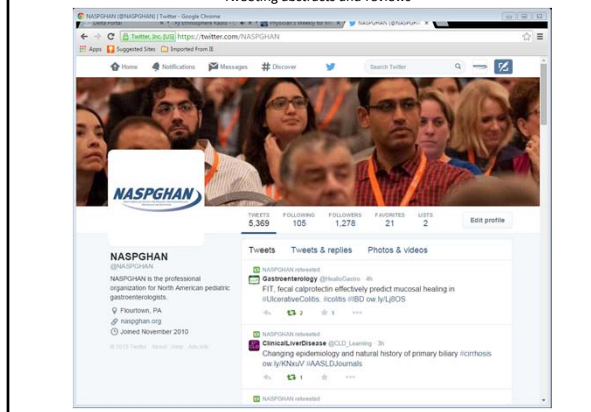
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## Tweeting abstracts and reviews




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## GIKids.org Twitter Feed




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## NASPGHAN Facebook Page




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## GKids.org Facebook Page




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## Basic MD Rules for Social Media

- Never provide specific patient information or advice.
- MOST useful for educating patients.
- Grow your network CAREFULLY (find people with similar interests).
- It is okay to be personal – not TOO personal.

<http://www.physiciansweekly.com/social-media-tips-doctors/>

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## Basic MD Rules for Social Media

- Don't lose your temper. I typically just ignore/block people.
- Retweet/repost articles from trusted sources.
- You need to stay involved. A quiet account is a dead account.

<http://www.physiciansweekly.com/social-media-tips-doctors/>

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## What Does the AMA say?

- Physicians should be “cognizant of standards of patient privacy and confidentiality.”
- Use privacy settings for safeguarding personal information (remember: Once on the web, always on the web, even with privacy settings).
- Maintain appropriate boundaries with patient interactions.

Opinion 9.124 – Professionalism in the Use of Social Media



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## What Does the AMA say?

- Best to maintain professional boundaries by separating personal and professional online content.
- When a physician sees content posted by a colleague that is unprofessional, 1) let that individual know or 2) contact authorities.
- On-line presence, if done incorrectly, can negatively affect reputation and undermine public trust.

Opinion 9.124 – Professionalism in the Use of Social Media



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## Other Aspects of Social Media

- Websites
- Podcasts
- Blogs
- Smart phone apps

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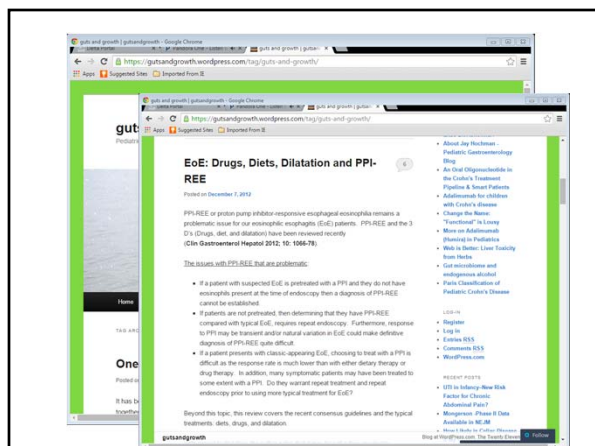
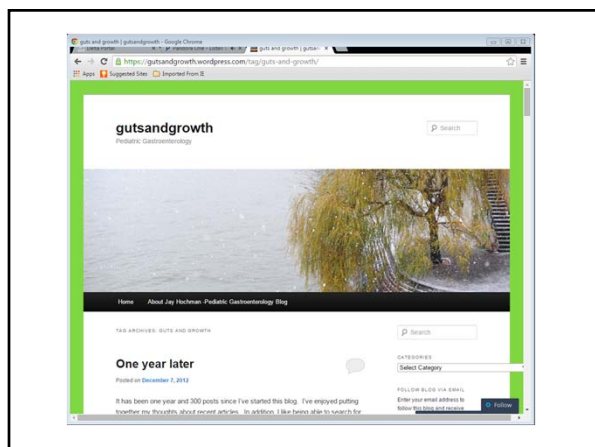
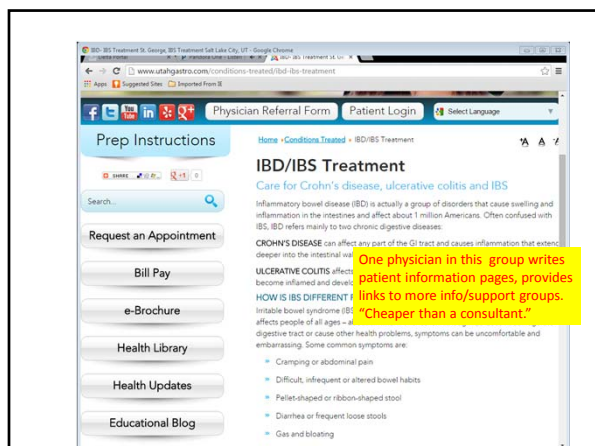
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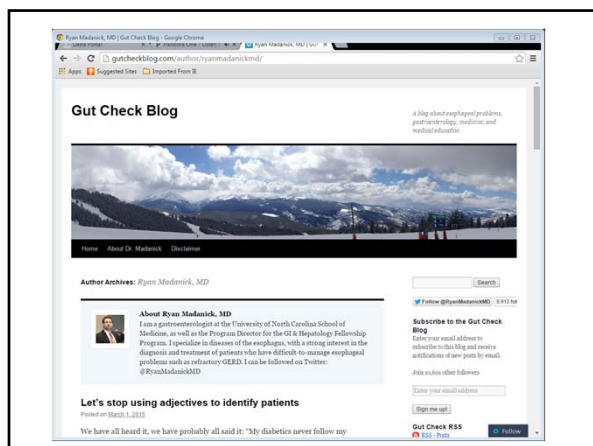
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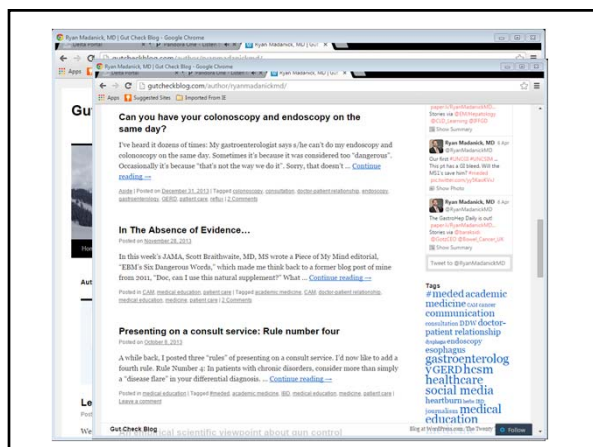
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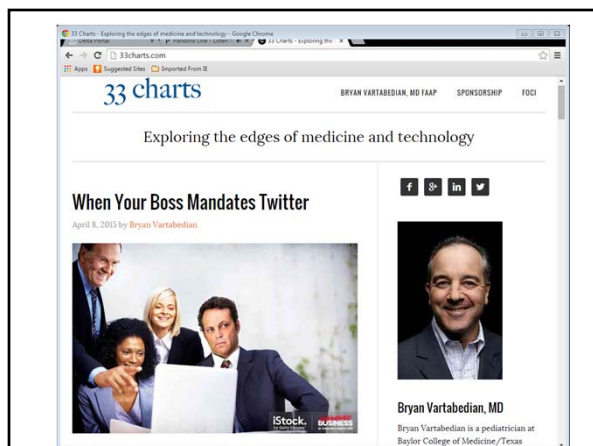
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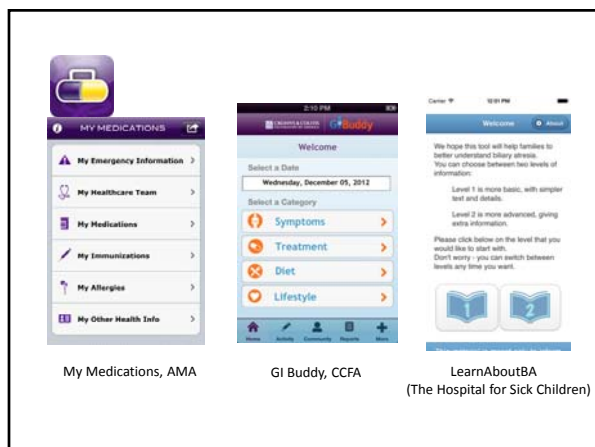
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### Summary:

- Our patients and their families are accessing on-line resources and social media to learn about their diseases.
- Our job is to help our patients and their families navigate the often difficult word of accurate information on-line.
- Consider exploring social media options to improve the care of your patients by networking and providing education.

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### Summary:

- Our patients and their families are accessing on-line resources to learn about their condition.
- Our job is to provide them with the most accurate information on-line.
- Consider exploring social media options to improve the care of your patients by networking and providing education.

Special thanks to :

1. Warren Bishop

2. Eric Benchimol

Thank You!

