The Role of Social Media in Promoting Emerging Disease Areas: Focus on The Field of Cardio-Oncology: #GCOS2018

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  - Stemline
  - Cellectis
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  - Daiichi Sankyo
  - Plexxikon
  - Samus
Speak Up!

The Moment that Changed How I Talk to My Patients

BY NAVEEN PEMMARAJU, MD

As an oncology fellow, the clinic I most look forward to every week is my leukemia clinic. However, I should also admit that the clinic I cringe going to the most every week is the very same leukemia clinic.

The truth is, though I have developed a strong affinity for the hematological malignancies and plan on devoting my professional life to the pursuit of the eradication of these diseases, I still have to mentally prepare each week before I walk into that clinic, given the degree of pathos and tales of overwhelming disease and heartbreak among some of our sickest patients.

A few months ago, I was asked to evaluate Mr. M., a patient with newly diagnosed chronic myeloid leukemia (CML). This is a patient interaction I was well adept at handling; I have seen many dozens of CML patients over the past few years. With the introduction of imatinib and subsequently, the second-generation tyrosine kinase inhibitors, this disease has been revolutionized over the past decade from one that was generally fatal within five years of diagnosis to now being one of the most highly treatable of all cancers. What I was not prepared for, however, was Mr. M.'s young age. He was only 21 years old.

I hadn't yet seen an adult leukemia patient this young. The median age for CML is around 67. It affects approximately 5,000 patients a year in the United States, with only a small fraction of these patients age 21 or younger. It was just so striking to see this robust young man—three years younger than the median age of the typical patient with CML, aervously

comforted myself. But, indeed I was more than a full decade older.

As I began interviewing this young couple, I learned that they had traveled to our center to inquire about the possibility of being enrolled onto a protocol with one of the second-generation tyrosine kinase inhibitors. I was prepared to discuss several options, including imatinib, or if he was indeed interested, ask him about one of our ongoing clinical trials. I had my speech ready to be delivered on our great successes and amazing outcomes with modern CML treatment.

But that’s not the exciting discussion my patient had in mind. What he was thinking about left me and the health care team utterly unprepared.

Then, several repeat visits later, it was becoming clear that he was going to refuse therapy all together. At the fourth visit, though, Mr. M’s wife spoke up. “We need to talk,” she said to me.

I pride myself on my history-taking ability, especially my social history-taking. However, one thing I failed to uncover in our visits was all of the life stressors my patient had before him. I found out that Mr. M.'s reluctance in taking our second-generation TKIs was actually due to concerns over his second generation.

The couple had been planning for some time earlier to start a family. Mr. M had noticed, though, that he was feeling more fatigued than usual and was newly needing to take naps to get through his day. His daily exercise workouts were becoming shorter, and shorter until he eventually stopped going at all because he was feeling tired all the time. And then within a week of seeking medical care, he had undergone a battery of tests, culminating with a bone marrow biopsy revealing the leukemia diagnosis.

His wife relayed to me that their hesitation about treatment was secondary to the fear of never being able to have children. Mr. M and his wife had very thoroughly read over the entire chemotherapy consent packet given to them at our first meeting. They dutifully read every page, line by line. They informed me that they had read the customary line about precautions for childbearing and risks of getting pregnant while on chemotherapy. Their silent worry about starting a chemotherapy that was in the form of a pill that had to be taken every

Pemmaraju N, Oncology Times Oct 25, 2010
The Case for Personalized Patient Communication: Era of Social Media, 2016
Twitter 101: Micro-blogging social media platform for 2016

• Social Media
  — To tweet = to send a message
• Tweet= 140 character message
• Real-time, worldwide
• Archived

• # = category, type, topic (e.g. #leusm)

• RT=Retweet
• MT=Modified tweet

• Twitter=March 2006; San Francisco
  — Present day: ~310 million active users
  — ~4,000 employees
  — Twttr/”SMS” of Internet→short bursts of information
Cancer Communication in the Social Media Age

- Lung cancer and Awareness of Clinical Trials

- N=26,059 tweets “lung cancer” from Jan 5-21, 2015
  - Nvivo data analysis software
  - 15,346 unique tweets
  - 10% selected at random (n=1516, excluded 19 tweets not in English)

- 83% = useful content; remaining=misc
  - 28% = support
  - 28% = prevention
  - 18% = clinical trials

- Among clinical trial tweets (n=221)
  - 82% = study drug trials
    - 79% = Immunotx
    - 86% had links to key articles
    - 1 tweet only → website for patient recruitment
  - 5% = basic research

Key: Enrollment in clinical trials → only ~5-7% of US adult cancer patient population

Sedrak MS et al JAMA Oncology June 2016
Blood website

- [http://www.bloodjournal.org/content/128/9/1193.long](http://www.bloodjournal.org/content/128/9/1193.long)

- Deep phenotyping of Tregs identifies an immune signature for idiopathic aplastic anemia and predicts response to treatment {Kordasti et al, Blood 2016 128:1193-1205}

- For every Blood article on website now: Article/Figures/Data/Info &Metrics/e-Letters/PDF

- [https://bloodjournal.altmetric.com/details/8634684](https://bloodjournal.altmetric.com/details/8634684)
  - Twitter summary
  - Attention score
  - Twitter demographics/worldwide

- Altmetric: [https://www.altmetric.com/](https://www.altmetric.com/)
### Resources

ASCO15 Education Book. Table 1 - [http://ow.ly/NwAZ5](http://ow.ly/NwAZ5)

<table>
<thead>
<tr>
<th>Title</th>
<th>Author(s) (Date)</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet, Social Media, Privacy Regulations, and Clinical Trials</td>
<td>Bogler O, Thompson MA, Miller RS (June 2, 2014)</td>
<td><a href="http://ow.ly/xEy8f">http://ow.ly/xEy8f</a></td>
</tr>
<tr>
<td>Social Media &amp; Academic Oncology – Challenges and Opportunities</td>
<td>Katz M (December 19, 2014)</td>
<td><a href="http://slidesha.re/1Jqa6B0">http://slidesha.re/1Jqa6B0</a></td>
</tr>
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- **ASCO Social Media**: [http://www.asco.org/about-asco/social-media](http://www.asco.org/about-asco/social-media)
- **Social Media and the Practicing Hematologist: Twitter 101 for the Busy Healthcare Provider** – Thompson et al. 2015. Current Hematologic Malignancy Reports.
- **Social Media Myeloproliferative Neoplasms (MPN)-Focus on Twitter and the Development of a Disease-specific Community: #MPNSM** - Pemmaraju et al. 2015. Current Hematologic Malignancy Reports.
Why do Patients use Social Media/Twitter? Cancer Communication

• Thematic content analysis: centered around Facebook
  – 1 year study time period
  – Followed use of Social media by families with child with ALL
  – N= 15,852 posts

  - 6 common themes that categorizes all posts:

• 1)Documentation of cancer experience/journey
• 2)Sharing emotional burden of caregivers
• 3)Promotion/awareness/advocacy pediatric ca.
• 4)As a means for fundraising
• 5)To galvanize support
• 6)Expression of gratitude to supporters
You are so busy. Why Twitter for the Physician-Scientist?

- **Outreach:** To provide patient/general population education, update public
- **Networking:** with other MD/scientists in your field and other fields
- **Personal Discovery:** To learn for yourself: latest papers in your field, other fields of interest
- **Personal Brand development:** highlight your work, your papers, your co-authors, mentees, institution
- **Societal benefit/duty:** to provide knowledge as scientist to rest of population/taxpayers
- **Highlight very rare diseases:** provide information when there is no great information available in a subfield
- **Medical conferences:** participation, leading discussions in real-time (esp for those not at meeting, following remotely)
- **Community:** starting, maintaining support groups, all stakeholders interested in a niche, common topic of interest
- **Archived information:** A brilliant way to track all of the information in a field: via searching, #/category, your own tweets, favorites

Activity & Contributors: Twitter Study

- Urologic Oncology

- Comprehensive Twitter hashtag (#) analysis for GU oncology hashtags (e.g. #prostatecancer, #kidneycancer)

- Powered by: Symplur analysis

- In 2014: 100,987 tweets by 39,326 contributors
  - Activity on Twitter increased by 41% in 2013; by 122% in 2014
  - 1) Awareness 2) Cancer and 3) Risk
  - 41 countries on 6 continents
  - Tweeted from mobile devices only (39%) > than Tweeting from desktop computer (29%)
  - Most tweets by MD’s came on topics: #prostatecancer & #kidneycancer

Borgmann H et al Urol Oncol 2016 Sep;34(9): 377-83
Medical Conferences

• Comprehensive study: 2013 European Association of Urology Congress (#eau2013):

• N=218 Twitter authors: MD (45%); associations (15%); companies (10%), journals (3%)

• Notably, journals → highest tweet: participant rate (22 Tweets/participants), profile activity

• Tweets with a link → led to higher engagement/popularity (p<0.0001)

• 88% tweets during conference hours

• Avg: 25 Tweets/hour; peak communication = 71 Tweets/hour
ASH

• MD conversations increased by 44% from #ASH13 to #ASH14

• And, the number of MD’s using twitter at ASH increased by 83% (n=133 to n=243)

• Ten Simple Rules of Live Tweeting from Medical Conferences (Ekins, Perlstein)

Slides: modified from M. Thompson
Growth of Physicians Tweeting During ASCO Annual Meetings

Number of doctors participating on Twitter during ASCO. Includes two weeks before and after each conference.

- #ASCO11: 111
- #ASCO12: 205 (↑85%)
- #ASCO13: 402 (↑96%)
- #ASCO14: 950 (↑136%)
- #ASCO15: 1,248 (↑31%)

@symplr
www.symplr.com

Slides: modified
from M. Thompson
Ten Simple Rules

- Rule 1: Short Conference Hashtag
- Rule 2: Promote the Hashtag (e.g. name badges)
- Rule 3: Encourage Tweeting
- Encourage live tweeting at the conference. Session chairs can facilitate this and relay questions from the twittersphere.
- Rule 4: Conference Twitter Etiquette
- Rule 5: Conference Tweet Layout
- Rule 6: Keep Conference Discussion Flowing
- Rule 7: Differentiate Your Opinions from the Speaker's
- Rule 8: Bring Questions up from Outside
- Rule 9: Meet Other Live Tweeters Face to Face
- Organize tweetups so that conference attendees can meet in person and consolidate relationships and collaborations.
- Rule 10: Emphasize Impact of Live Tweeting
- Ensure that positive effects of tweeting at conferences, such as discoveries, publications, or collaborations, are highlighted.

How to Organize, Aggregate all of this information?

- **Symlur.com**
  - Healthcare analytics
  - Free, open platform: HealthCare Hashtag project

- **Cancer Tag Ontology (CTO)**
  - M. Katz et al
  - Disease-specific hashtags to help organize, archive information by category of cancer
    - First 2: #bcsm (breast cancer social media);
      #btsm (brain tumors social media)
    - Especially to highlight rare cancers

Who to Follow on Twitter: Heme/Onc

- Eric Topol @EricTopol [91.9K, 2009]
- Mike Thompson @mtmdphd [12.5K, 2010]
- Anas Younes [14.2K, 2009]
- Matthew Katz [13.4K, 2009]
- AACR @AACR [40.3K, 2008]
- ASH @ASH_hematology [16.6K, 2009]
- ASCO @ASCO [53.7K, 2009]
- NIH @NIH [657K, 2008]
- Blood @bloodjournal [4,590, Aug 2015]
- JCO @JCO_ASCO [1,778, Mar 2014]
- NEJM @NEJM [350K, 2009]
- Cell @CellCellPress [41.6K, 2009]
- Science @sciencemagazine [753K, 2009]
- Nature @nature [469K, 2012]

Compiled by Pemmaraju: Twitter, 9/2016
#MPNSM: Creation of a new Twitter Community: @doctorpemmm et al

Social Media and Myeloproliferative Neoplasms (MPN)—Focus on Twitter and the Development of a Disease-specific Community: #MPNSM

Naveen Pemmaraju¹ • Vikas Gupta² • Ruben Mesa³ • Michael A. Thompson⁴
#MPNSM: An ongoing Twitter conversation about MPNs

- Inspired by: CTO (based on #hcsm & #btsm) (Katz et al Disease-Specific hashtags for online communication about cancer care - JCO. 2015;33 suppl abstr 6520); and for hematology specific influence, #mmsm

- Founder of #MPNSM Twitter community: Naveen Pemmaraju, MD @doctorpemm
  - With key co-founders: @mtmdphd, @Vikas_Gupta_1, @mpdrc

- First tweet: @doctorpemm [Aug 2014] → but #mpnsm did not really take off as a regular hashtag until Dec’14-Jan’15: during/after #ASH15 meeting

- As of Sept,13,2015: For #MPNSM, According to @symplur @healthcarehashtags project: Jan’15-Sept’15
  - 2013 tweets from 285 participants
  - Resulting in: 4,049,415 impressions

- Brings together, in real-time: investigators/researchers, MPN healthcare providers, patients, advocates, organizations for discussion of basic science, translational, and clinical topics in MPNs
#MPNSM: Analytics of the First Year

- Study period/Symplur: Jan 1, 2015-March 31, 2016
- We found 513 unique users tweeting under #MPNSM
- N=4598 tweets
- **9,360,499 impressions** created (compared in their first 15 months to 7,843,105 impressions for #leusm and 27,173,622 impressions for #mmsm)
- In its first year, the most common group using #MPNSM → MDs (42%)
- Remarkably, a very low spam rate (non-true-user rate only 1.8%) for this unique hashtag
- Peak use in first year for #MPNSM: Dec 5, 2015
  - #ASH15; 166 tweets on this day alone
  - Most RT/impressions during ASH from #MPNSM: @doctorpemm 17 fav/10 RT [Tweet during plenary session on splicing/mutational biology slide]
Selection of Physician-Investigators Mentioned on #MPNSM

<table>
<thead>
<tr>
<th>Physician</th>
<th>Twitter handle</th>
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<tbody>
<tr>
<td>Naveen Pemmaraju, MD</td>
<td>@doctorpemm</td>
</tr>
<tr>
<td>Mike Thompson, MD, PhD</td>
<td>@mtmpdphd</td>
</tr>
<tr>
<td>Vikas Gupta, MD</td>
<td>@Vikas_Gupta_1</td>
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<tr>
<td>Ruben Mesa, MD</td>
<td>@mpdrc</td>
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<tr>
<td>Alison Moliterno, MD</td>
<td>@mpncare</td>
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<tr>
<td>Angela Fleischman, MD, PhD</td>
<td>@MPNlab</td>
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<tr>
<td>Stephen Oh, MD, PhD</td>
<td>@mpndoc</td>
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<tr>
<td>Aaron Gerds, MD</td>
<td>@AaronGerds</td>
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<tr>
<td>Laura C. Micahelis, MD</td>
<td>@lauracmichaelis</td>
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<tr>
<td>Navneet Majhail, MD</td>
<td>@BldCancerDoc</td>
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<tr>
<td>Muzaffar Qazilbash, MD</td>
<td>@TransplantDoc</td>
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<tr>
<td>Miguel Perales, MD</td>
<td>@DrMiguelPerales</td>
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<tr>
<td>Krishna Komanduri, MD</td>
<td>@drkomanduri</td>
</tr>
<tr>
<td>Nitin Jain, MD</td>
<td>@CLLdoc</td>
</tr>
<tr>
<td>Tapan Kadia, MD</td>
<td>@TapKadia</td>
</tr>
<tr>
<td>Malin Hultcrantz, MD</td>
<td>@malinhultcrantz</td>
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<tr>
<td>Mohamad Mohty, MD</td>
<td>@Mohty_EBMT</td>
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<tr>
<td>Bill Wood, MD</td>
<td>@WoodBD</td>
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<tr>
<td>Aziz Nazha, MD</td>
<td>@AzizNazhaMD</td>
</tr>
<tr>
<td>Toyosi Odenike, MD</td>
<td>@myeloidmalign</td>
</tr>
<tr>
<td>Gaby Hobs, MD</td>
<td>@GabyHobbs</td>
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Who else is using #MPNSM? Groups & Organizations. From 3/6/18

CONTi-PV: a 2-year follow-up of interferon product AOP2014
Interesting results were produced in the PROUD-PV Study (NCT01949805), which compared the treatment of ropeginterferon alpha-2b with hydroxyurea...

VJHemOnc @VJHemOnc · 6h
VIDEO: CONTi-PV: a 2-year follow-up of #interferon product AOP2014. with @jkladjian of @ParisDiderot_ow.ly/MclK30ikI3v @ASH_hematology #ASH17 #biomarkers #CTSM #caxtx #PV #policythemiavera #mutations #cgenome #immunoonc #MPNs #JAK2 #mpnsnm #hemeonc #hemonc #frontline

Aaron Gerds MD Retweeted
MPN Ad&Ed Int’l @mpnadvocacy · Mar 6
March MPN Community Connection Newsletter has posted- great info including San Antonio Video Presentations. MPN Patient events, an more conta.cc/2D40nRB #MPNSM pic.twitter.com/09SDGTTHpK

Patient Power @PatientPower · 6h
How does having a rare cancer like an #MPN impact daily life? Dr. Yacoub of @KUMedCancer with Dawn Urbanovsky & Julie Huynh-Lu from @MDAndersonC...
#MPNSM – Expanding into other writing/editing opportunities

Section Editor for two medical journals for #SoMe:

- Seminars In Hematology
- Current Hematol Malig Rep
#MPNSM: Analytics of the 2nd Year

- Increase in number of tweets (from 3,462 to 5,627) in 2nd time period (Jan 2, 2016-Jan 1, 2017)

- Increase in # of unique users, Twitter impressions, Retweets (RT)

- **Most RT’d post:** @cure_magazine: “We talked to @doctorpemmm about the importance of open patient-physician conversations #mpnsm http://www.curetoday.com/articles/on-twitter-mpn-patients-and-physicians-connect-in-real-time https://t.co/ERKc796hBS” (RT n=16; Jun 28, 2016 at 11:28 AM)

- **2nd:** @jnccn: #NCCN Publishes New Clinical Practice Guidelines for Myeloproliferative Neoplasms: http://bit.ly/2cSlw59 #mpnsm (RT=11; Tue, Sep 27, 2016, 5:35 AM Medical journal)

- **3rd:** @malinhultcrantz: “@doctorpemmm doing a great job moderating the MPN session! #ASH16 #mpnsm https://t.co/iOYbvS8I1L (RT n=10; Mon, Dec 5, 2016, 3:16 PM Academic physician)
#MPNSM – Builds connections in a rare disease field

- ASH – insight/debate/discussion
- Connecting with other KOL
- Collaborations/Projects
- Tweet-ups
- Latest papers in the field/pubmed link
- Connecting with patients/caregivers/general population
- Connecting with NPO, patient advocacy organizations
Social Media and Internet Resources for Patients with Blastic Plasmacytoid Dendritic Cell Neoplasm (BPDCN)

Naveen Pemmaraju1 · Vikas Gupta2 · Michael A. Thompson3 · Andrew A. Lane4

- #BPDCN: Twitter community
- www.BPDCNinfo.com
- MD Anderson OncoLog
- LLS: www.lls.org
- Blogs: BPDCN 2016, A Cancer Survivor Story: patient of Dr. Pemmaraju
#BPDCN: Creation of a new Twitter Community

- Orphan/Rare disease → awareness; education; to provide updates
- First month (Symplur) analytics: April-May 2016
  - 91 tweets from 31 participants
  - Already 281,780 Twitter impressions
- Interview by @doctorpemm with @ASHClinicalNews at #ASCO16 on oral presentation topic for #BPDCN → 15 RT/11 fav during meeting (June 2016)
  - Topic of BPDCN at this year’s ASCO was thus able to reach many more people via amplification on social media

Pemmaraju N et al Social Media and Internet Resources for Patients with BPDCN, Curr Hematol Malig Rep 2016
AYA patients with Cancer

- Pew Research Center: 2/3 US Adults use social media sites; Among US adolescents & young adults (AYA): 90% (ages 18-29)
- Personal Blogs or Webpages
- Online Clinical Forums (ASBMT CCF: professional discussion experts in SCT, 137 cases posted/discussed)
- Hashtags and Tweet Chats (“Tweet-ups”): #AYACSM
- Patient-Generated Health Data Cohorts
  - Apple’s “Research Kit” (www.apple.com/researchkit) hosts large cohort studies, e.g. “Share the Journey” study for breast cancer survivors
  - FitBit, support/exercise groups, other wearables
- Organizations for AYA patients with Cancer
  - Including all with social media presence, Twitter handles (e.g. @heycriticalmass, @CancerFightClub, @hope4yawc, @StupidCancer

Perales, M, Drake EM, Pemmaraju N, Wood W. Social Media and the Adolescent and Young Adult (AYA) Patient with Cancer. Curr Hematol Malig Rep, 2016
Privacy, Pitfalls, Limitations

- Approach information with vigilance, cross-check, beware of misinformation
- Lack of curation, oversight, accountability
- Concerns for patient privacy/confidentiality
- Concerns for MD/scientist: medico-legal, giving inaccurate info, changing info, controversy, giving one’s own opinions

Source and Credibility:
- Twitter Study (Park S et al)
  - N=76,199 tweets analyzed over 3 mos
  - Colorectal ca
  - Individual authors: 91%
  - 1) medial/news articles, 22%, 2) risk/prevention 19%
  - Credibility analysis: most Tweets medically accurate, 85%

Audience Participation

• Time to apply what you have learned!
• #1: How many of you are already on Twitter?
  – A: Yes and I’m a big fan
  – B: Yes, but I rarely look at it
  – C: No, but I’m thinking about it
  – D: What’s Twitter, again?
Audience Participation

• Time to apply what you have learned!

• #2: How many of you actually use Twitter for professional purposes?
  - A: Yes
  - B: No
Audience Participation

• Time to apply what you have learned!

• What are some reasons you could use Twitter as a busy cardiologist or hematologist/oncologist?

• How/when/why use #CardioOnc?
#CardioOnc

- Use this hashtag in your tweets
- Quick, easy way to go back and search (archived)
- Allows all stakeholders to follow along
- Decreases spam!
Audience Participation

• Time to apply what you have learned!

• How to Tweet using proper hashtags? Let’s do it together right now! {LIVE DEMONSTRATION} Use the right hashtag: #GCOS2018

• It’s hard to do your first tweet; Dear Ben story
Audience Participation

• Time to apply what you have learned!

#5: Never used Twitter before? Let’s sign you up… right now!

@ = your handle /alias/name: think of something clever, unique, that encompasses your professional interests

# = hashtag /category (can be real or made-up by you!)

Character limit: includes spaces
Conclusions

• Social Media for rare diseases, rare hematologic malignancies, new inter-disciplinary fields / fosters #CrossTalk

• Little available expert information; sometimes misinformation or no info at all → up to us as experts to fill this information void

• Opportunity to highlight a particular area of research in extremely rare diseases or new areas (e.g. #BPDCN, #MPNSM, #CardioOnc, #ImmunoOnc)

• Networking w/colleagues, other experts, community doctors, patients, referral base, clinical trial recruitment & name recognition

• Medical conferences-enhances in person experience; or “virtually attend”/ “remotely attend” and contribute to discussion: #GCOS2018
Acknowledgements

- **Mike Thompson @mtmdphd**
- Michael Fisch @fischmd
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- Navneet Majhail @BldCancerDoc
- Aaron Gerds @AaronGerds
- Robert Orlowski @Myeloma_Doc
- Krishna Komanduri @drkomanduri
- Tapan Kadia @TapKadia
- Nitin Jain @CLLdoc
- MD Anderson Leukemia @leukemiamda

- **#MPNSM:**
  - Vikas Gupta @Vikas_Gupta_1
  - Ruben Mesa @mpdrc
  - Mike Thompson @mtmdphd

- **#BPDCN:**
  - Vikas Gupta @Vikas_Gupta_1
  - Mike Thompson @mtmdphd
  - Andy Lane @lane_andy

- **#AYACSM:**
  - Miguel Perales @DrMiguelPerales
  - Emily Drake @EK_Drake
  - Bill Wood @WoodBD