Hope and support for affected individuals and their families through research, advocacy, and awareness
Training objectives

- Share information about the efficacy of social media as an advocacy tool
- Provide examples of social media advocacy
- Describe how to get started and how to increase your effectiveness
- Provide recommendations about best practices and guidelines
- Distribute template messages
10 years of big changes
first for the kids...then the adults...
The next big thing
Bitly? Hashtag? Twitterverse? What?

@jack
Jack Dorsey

just setting up my twttr
21 Mar 06 via web    Favorite Retweet Reply

Retweeted by anyulled and 100+ others
How often are you active on FB?
How frequently do you tweet?
Why bother?
Why bother?

It’s where nonprofits and advocates are (97%)
Why bother?

Lawmakers have entered the fray

It’s where nonprofits and advocates are (97%)
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WHY to use social media for advocacy is more important than HOW to do it.
Thanks #MASen for passing the Healthy Kids Act & Sen. @TomMcGeeDSC for your leadership & @MeaghanHamill for your tireless advocacy!
Passionate discussion about getting transparent to drive improvement for

#HLHS. #NPCQICLS
In major step forward for paid sick leave, Jerry Brown signs law guaranteeing paid sick days to California workers.

abc30.com/politics/gover...
Tayla Andre @Tayla_Andre · Sep 16
@SoniaChangDiaz had you spearheaded #liftheccap thousands of children could attend quality high schools, obtain a competitive education

Tayla Andre @Tayla_Andre · Sep 16
@SoniaChangDiaz my child should have access to a better education!
#liftheccap #chariersschools #WakeUpwithTaylaAndre
pic.twitter.com/OI2zafR6pN

Enclosed in this envelope you will find the Independent School Entrance Exam (ISEE) Registration Form. The ISEE is the entrance exam for Boston Public Exam School, Boston Latin School, Boston Latin Academy, and John D. O'Brien School. All students who are Boston residents in the 6th and 8th grade are eligible to apply. Schools, however, this is not required. The BPS Residency Policy and Schedule

If you are interested in having your child take the ISEE test, and apply to an entry, turn these documents and have your scholar return the completed Registration Form by September 19th. Please do not mail this form – it should be sent back to be important that we meet this deadline to ensure a seat on the test date on

The following are the school codes for question 8 – School Now Attended
Brooke East Boston 5452
Brooke Mattapan 5451
Brooke Roslindale 5450

Please select from the following test center options, and their codes:
Boston Latin School, Boston - W257

Sindication @OneHeadlightInk · Aug 27
Don't stifle the New Mexico Film Industry ever again
sacurrent.com/screens/film/n... Saves filmmakers money & time, makes $$$ for NM #LiftTheCap
#istandupfor #lungcancerpeople like Molly who wants to live to see her little girls grow up. #SU2C @nbcbayarea #lcsm
DO YOU KNOW STEPHANIE?

If you know Stephanie, send her a message.

PHOTOS

Stephanie Belle Mays Bozarth shared a link via Morquiosis.

Yesterday

Expert education on the surgical concerns in Morquio A – Understanding the risks of anesthesia ....
event.webcasts.com

There are serious risks associated with the use of anesthesia in Morquio A. Join us as Dr. Mary Theroux, anesthesiologist at A.J. DuPont Hospital for Children, reviews the reasons for this high risk and measures to avoid surgical complications. You'll have...

Share

Stephanie Belle Mays Bozarth

September 20

Hola...at erasure concert relivin it!!! — with Celeste Dewitt Crutchfield.
Here we go... 126 miles here I come! Still not to late to donate to the cause: http://www.harbortothebay.org/profile/Gustavo.Torrez/ — at Trinity Church.
Diane McDonnell Pickles shared a link.
February 28

I have been advocating for this legislation as a volunteer for the American Heart Association — Massachusetts for what feels like a LONG time. The House and Senate passed it yesterday and we now need the Governor's signature for it to be law and to make sure that every baby born in Massachusetts is screened for heart defects with this simple, inexpensive, painless test. If you are a Massachusetts resident, please join me in asking Governor Patrick to sign the bill and make it LAW.

You're The Cure
yourethecure.org

I just took action on AHA's You're the Cure website: The 45 Second Test That Can Save a Life...
Getting started

- Get comfortable
- Follow your lawmakers and relevant health and news reporters/outlets and bloggers
- Follow relevant health organizations (i.e. NORD)
- Follow one another
- Follow news, read blogs, and pay attention to what decision makers and organizations are saying
Getting stronger

- Actively and intentionally grow your network (who you follow and who follows you)
- Leverage content from others – share and retweet
- Be conversational
- Be a good friend to other advocates
- Pay attention and participate actively
- Treat social media as a powerful tool – not a time waster!

Your power comes from persistence and the reach of your network.
Helpful Guidelines

Represent yourself
Helpful Guidelines

Use shared hashtags, i.e. #cureemps

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Helpful Guidelines

Represent yourself

Best practices:
- Make it personal
- Use visuals
- Be yourself

Use shared hashtags, i.e. #curemmps

“Boost” society action alerts, events, and fundraisers

Be edgy but not disrespectful
Plug and play
Promote the Society’s Rally

Please join me in rallying for MPS! With your help, the National MPS Society will be able to continue to fund life-saving research and support families like mine. Click here to rally!

Let's rally for MPS! Your support means the world to me and my family. https://rally.org/f/hQfGaF/xoCkL #curemps

Raise money for MPS research
Welcome back your members of Congress

Welcome back to DC Senator [NAME]. MPS diseases don’t take vacations or days off. As you get back to work in Congress, please fight for rare diseases like MPS. Families like mine need a cure. You can learn more about MPS here: http://mpssociety.org/

Welcome back to DC @[SENATOR’S HASTAG]. MPS diseases don’t take vacations. My family needs your help! http://mpssociety.org/ #curemps

Build a relationship
Educate members of Congress
Ask your members of Congress to join the Rare Disease Caucus

Senator [NAME], my family lives in hope that one day a cure for MPS will be discovered. Will you help us by joining the Rare Disease Caucus?
http://rareadvocates.org/rarecaucus/

@[TWITTER HANDLE], my family lives in hope of a cure for MPS. Will you help by joining the Rare Disease Caucus?
http://rareadvocates.org/rarecaucus/#curemps

Make an ask of lawmakers
Ask friends to invite their members of Congress to join the Rare Disease Caucus

As family and friends, you know the struggles that MPS has brought to my family. So often people ask, “How can I help?” Here’s one super quick and easy way – urge your members of Congress to join the Rare Disease Caucus. Thank you! [http://bit.ly/Rare-Caucus](http://bit.ly/Rare-Caucus)

 Urge friends and family to take action

[@TWITTER HANDLES], can you spare 2 minutes to help families like mine impacted by MPS? Click here [http://bit.ly/Rare-Caucus](http://bit.ly/Rare-Caucus) #curemps
Poll question

How will you engage?
Questions, Answers, and Discussion
Thank You