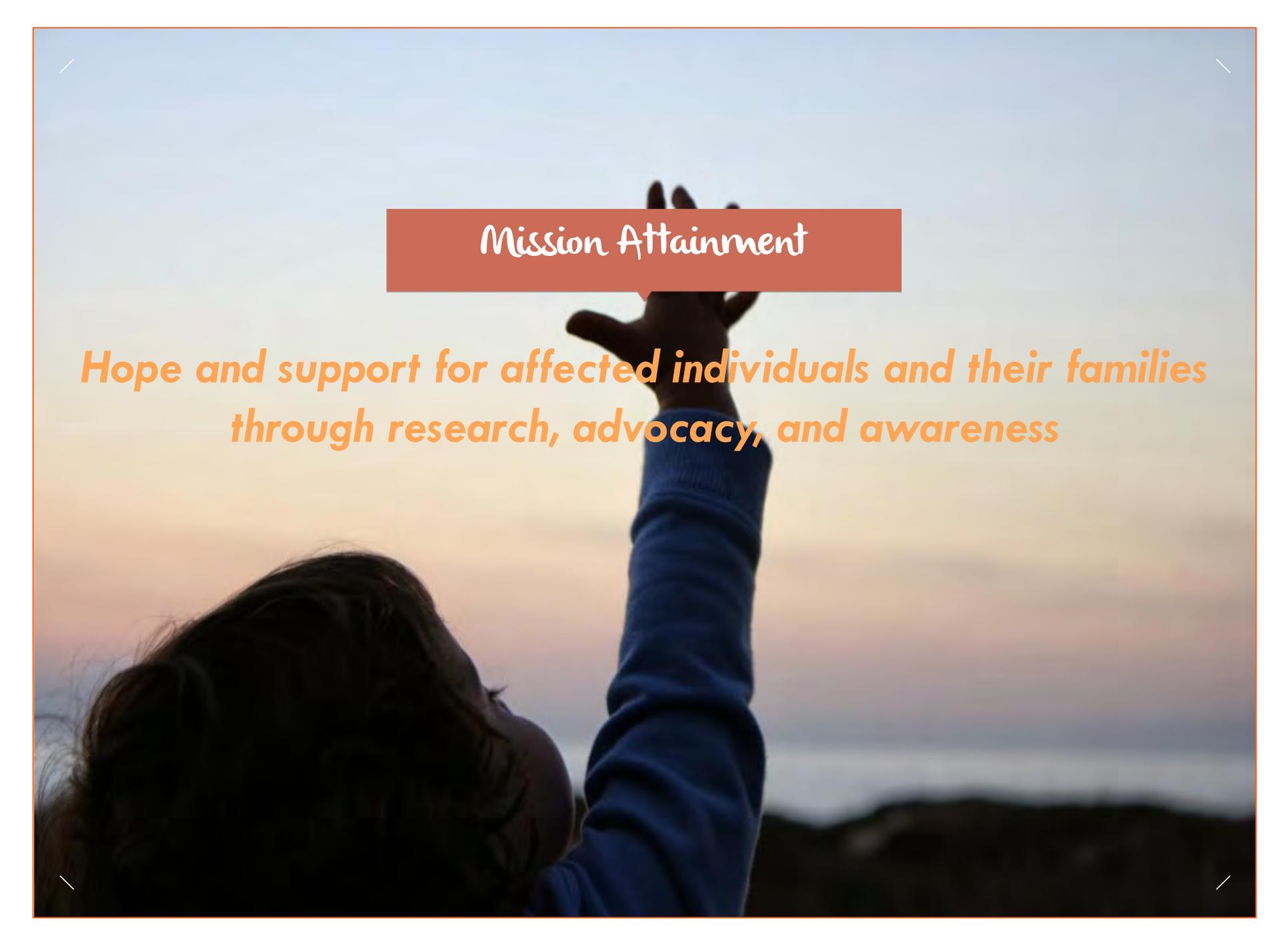


Social Media Advocacy
National MPS Society

Diane M. Pickles

A person is shown from the back, reaching their right arm up towards a sunset sky. The person is wearing a blue long-sleeved shirt. The sky is a mix of orange, yellow, and blue, with a dark horizon line. The overall mood is one of hope and aspiration.

Mission Attainment

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



Survey says...

How often are you
active on FB?
How frequently do
you tweet?

Why
bother?

Why bother?

It's where
nonprofits and
advocates are
(97%)

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Lawmakers have
entered the fray

Why bother?

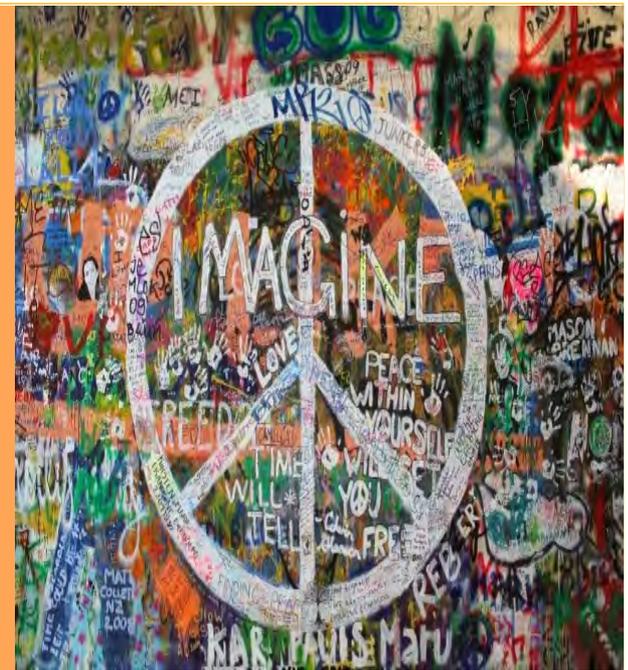
It's where nonprofits and advocates are (97%)

Lawmakers have entered the fray

Access to reporters, bloggers, and other influencers

Why bother?

It's where nonprofits and advocates are (97%)



Lawmakers have entered the fray

Access to reporters, bloggers, and other influencers

Quick way to reach lots of people, spanning geography and time zones (they don't call it viral for nothin'!)

WHY ?

**WHY to use social media for
advocacy is more important than
HOW to do it.**



 **Allyson Perron** Following
@APerronHasHeart

Thanks #MASen for passing the Healthy Kids Act & Sen. @TomMcGeeDSC for your leadership & @MeaghenHamill for your tireless advocacy!

Reply Retweeted Favorite More

RETWEETS 4 FAVORITES 3 

9:19 PM - 30 Jul 2014

 Reply to @APerronHasHeart @TomMcGeeDSC @MeaghenHamill

Trends

#OneMoreDay Promoted by MasterCard #Lab14 Vince Vaughn Doug Ford Jesse Matthew
#NCISNewOrleans #ShawnsFirstHeadlines #Climate2014 #TheVoice True Detective



Diane Pickles
@dmpickles

Passionate discussion about getting transparent to drive improvement for #HLHS. #NPCQICLS

Reply Favorite More

RETWEET
1

FAVORITES
5



2:14 PM - 25 Apr 2014



Reply to @dmpickles

Trends

#OneMoreDay Promoted by MasterCard #Lab14 Vince Vaughn Doug Ford Jesse Matthew #NCISNewOrleans #ShawnsFirstHeadlines #Climate2014 #TheVoice True Detective



Steven Greenhouse
@greenhousesny



Follow

In major step forward for paid sick leave, Jerry Brown signs law guaranteeing paid sick days to California workers.
abc30.com/politics/gover...

Reply Retweet Favorite More

ABC30 Fresno

Governor Brown signs bill giving paid sick leave to California workers

Gov. Jerry Brown signed legislation Wednesday that will require most California employers next year to provide up to three sick days for millions of workers.



[View on web](#)

RETWEETS
35

FAVORITES
17



9:03 PM - 10 Sep 2014

Flag media

Reply to @greenhousesny

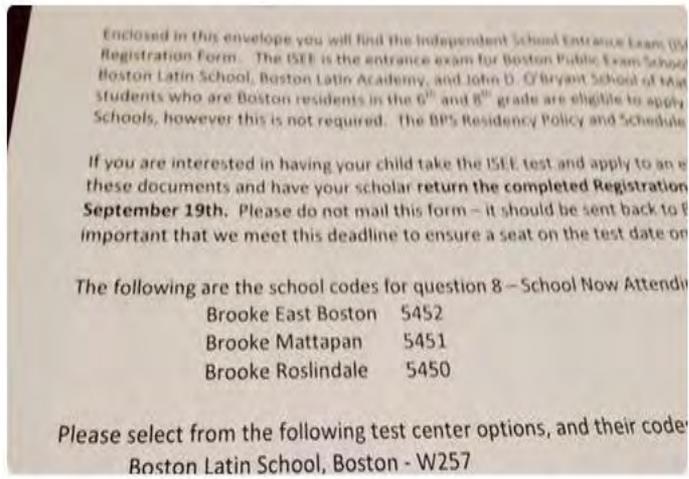


Tayla Andre @Tayla_Andre · Sep 16
@SoniaChangDiaz had you spearheaded #liffthecap thousands of children could attend quality high schools, obtain a competitive education

Expand



Tayla Andre @Tayla_Andre · Sep 16
@SoniaChangDiaz my child should have access to a better education! #liffthecap #charterschools #WakeUpwithTaylaAndre pic.twitter.com/O1ZzafR6pN



Expand



@Sindicacion @OneHeadlightInk · Aug 27
Don't stifle the New Mexico Film Industry ever again! sacurrent.com/screens/film/h... Saves filmmakers money & time, makes \$\$\$ for NM #LifftheCap

Expand



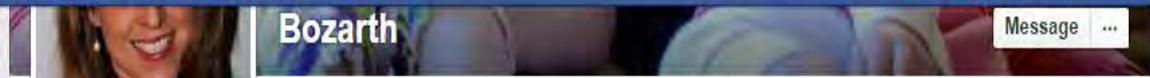
Faces of Lung Cancer
@LungCancerFaces

Follow

#istandupfor #lungcancerpeople like Molly who wants to live to see her little girls grow up. #SU2C @nbcbayarea #lcsm

Reply Retweet Favorite More





Bozarth

Message ...

Timeline About Photos Friends More

DO YOU KNOW STEPHANIE?
If you know Stephanie, send her a message.

PHOTOS



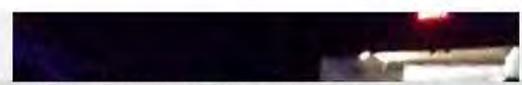
Stephanie Belle Mays Bozarth shared a link via Morquiosity. Yesterday

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.I. 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

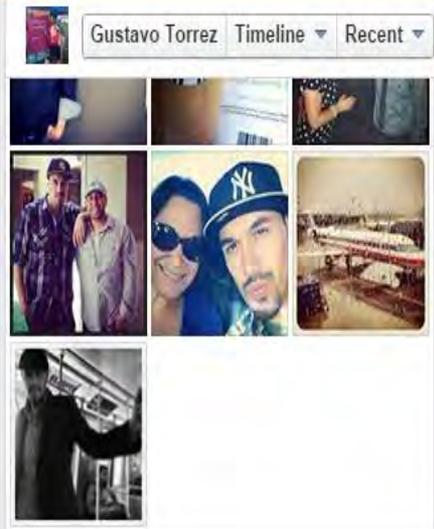
Hola...at erasure concert relivin it!!!! — with Celeste DeWitt Crutchfield



The Container Store®
containerstore.com
Shop Our Annual Shelving Sale - 25% off shelving AND Installation. Show off your Shelfies!

Recent
2014
2013
2012
2011
2010
2009
2008
Born

- Carrie Byrne Join in!
- Kelly MacFarland likes Bobby Kleinau's status.
- Barbara Kibit O'Neil shared a link.
- Kim D'Alleva Mobile
- Susan McDonnell... Web
- J.P. McCormick Web
- Erica Dudenhoeffer Mobile
- Gavin Monagle 22h
- Madonna Aldrich Mobile
- Matt Robertson Mobile
- Amy Shope Manzi Web
- Beth S Richards Web
- Jim Byrne Web
- Casey Bolton Mobile
- MORE FRIENDS (15)
- Barbara Kibit O'... Mobile



Gustavo Torrez
September 20

Here we go... 126 miles here I come! Still not to late to donate to the cause:
<http://www.harborotothebay.org/profile/Gustavo.Torrez/> — at Trinity Church.



Like Comment Share

49 people like this.

Recent
2014
2013
2012
2011
2010
2009
Born

- Deborah Carrozza Noone likes Cheryl Speers Waitt's link.
- Carrie Byrne Join in!
- Kelly MacFarland likes
- Michelle Doria-C... Mobile
- Patty Credit-Flana... Web
- Kim D'Alleva Mobile
- Lisa Bayha Deck Web
- Susan McDonnell ... Web
- Kristin Vickery Mobile
- Gina Schoenfeld Mobile
- Seana O'Connell Mobile
- Jonathan Dunn Web
- Becky Meharg Mobile
- Michael Katchman Mobile

Sponsored



Bed Bath and Beyond
bedbathandbeyond.com
Shop the Brands You Love & More. Free Standard Shipping on All Orders Over \$49.

MORE FRIENDS (20)

- Amy Shope Manzi Web

RECENT ACTIVITY

Gustavo is now friends with Felecia King and 9 other people.

Gustavo likes The Boston Sisters of Perpetual Indulgence.

Gustavo went to Beantown Softball League Awards Banquet.

Diane McDonnell Pickles Timeline 2014 Highlights



Like · Comment · Share 21 4

More posts from February 28 to March 4

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

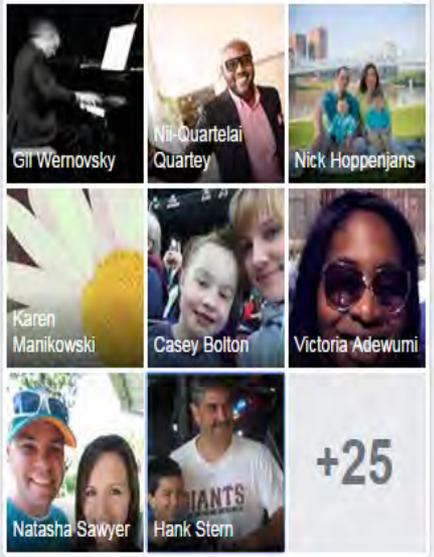
I just took action on AHA's You're the Cure website: The 45 Second Test That Can Save a Life...

Like · Comment · Promote · Share 9 2

More posts from February 27 to 28

Diane McDonnell Pickles February 27

FRIENDS · 2014



LIKES · 2014



- Recent
- 2010s
- 2014
- 2013
- 2012
- 2011
- 2010
- 2000s
- Born

Joe Parent commented on his own link.

Kathy Collins Sullivan likes Jennifer Ward Scarci's status.

Michelle Robertson likes

Allison Sherlock ... Mobile

Amy Gerrish Bennett Web

Elizabeth Cooper Mobile

Lisa Bayha Deck Mobile

Emma Fennessy Mobile

Erica Dudenhoeffer Mobile

Kathy Collins Sulli... Web

Gavin Monagle 22h

Matt Robertson Mobile

Carole Lannon Mobile

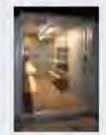
Lisa Mugavero ... Mobile

MORE FRIENDS (13)

Carrie Byrne Mobile

Sponsored

Mini Warehousing Storage
miniwarehousing.com



Got Space? We do! We bring On Site, Secure Storage Containers in Massachusetts to you!



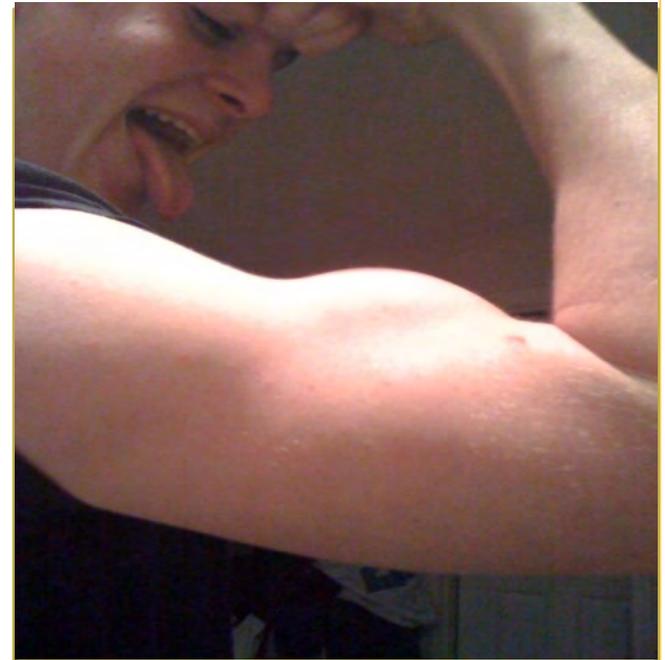
Getting started

- * 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

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Represent
yourself

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yourself

Use shared
hashtags, i.e.
`#curemps`

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“Boost” society
action alerts,
events, and
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Helpful Guidelines

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hashtags, i.e.
#curemps

“Boost” Society
action alerts,
events, and
fundraisers

Be edgy but not
disrespectful

Helpful Guidelines

Represent
yourself

Best practices:

- Make it personal
- Use visuals
- Be yourself

Use shared
hashtags, i.e.
#curemps

“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!](https://rally.org/f/hQfGaFXoCkL)

Let's rally for MPS!
Your support means the world to me and my family.
<https://rally.org/f/hQfGaFXoCkL>
[#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://rareadvocate.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>

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

Urge friends and family to take action

poll question

How will you
engage?

Questions, Answers, and Discussion

Thank You
