#RareDC2016

*Silence your cell phones please*
Welcome to Advocacy on Social Media

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Facebook Case Studies

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Twitter Basics

Twitter is the best social tool for sharing key messages and information with targeted audiences by engaging them directly or through mutual interests.
Twitter Basics: Handles

- Handles are a chosen screen name after the @ symbol.
- Handles are unique to an individual or organization, like an email address.
- When you want to make sure that someone sees your message, include their handle in your Tweet so they receive a notification.
- Must-follows in rare disease:
  - @CuretheProcess
  - @RareAdvocates
  - @GlobalGenes
  - @RareDiseases
  - @Eurordis
  - @RareDiseaseUntd
  - @ORDR
  - @RareDiseaseDay
@CuretheProcess

- Focuses on Foundation programs and events as well as science-based public policy

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Action alert: Pls ask your Senators to co-sponsor OPEN ACT to provide incentives to repurpose drugs for raredisease ow.ly/WIU8t

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Please join coalition to urge Senate Committee leaders to release companion legislation for #Cures2015 ow.ly/X26r3 #CuresNOW
@RareAdvocates

- Focuses on federal and state advocacy including action alerts from other advocacy organizations.
Twitter Basics: Your Bio

• Mention #raredisease and/or your individual rare disease in your Twitter bio.
• Include a link to your webpage, blog or Facebook page. Make it easy to learn more!
Twitter Basics: Hashtags

- Hashtags are words or phrases that follow the # symbol in Twitter.
- Using hashtags helps people interested in specific topics find you and your tweets. They are like the label on a file folder.
- Find (or create) a hashtag for your specific rare disease to make it easier to find and share relevant content.
- Examples (broad): #RareDisease & #clinicaltrials
- Examples (more specific): #GaucherDisease & #Duchenne
Twitter Basics: Hashtags

Use trending hashtags to add the voice of the rare disease community to more general discussions.

RDLA @RareAdvocates

Congress can make our #scibucketlist happen. Pass #cures2015 to better leverage 21st century science to develop new #raredisease treatments!

9:41 AM - 11 Dec 2015

Campaign for Cures @Campaign4Cures

.@LesterHoltNBC, 30M Amer. live w/ a #RareDisease. If elected how will you ensure research to find cures? bit.ly/1RrNXYA #DemDebate

5:06 PM - 15 Jan 2016
Add Followers

• The easiest way to get new followers is to follow people and organizations with similar interests.
• Search the hashtags of greatest interest to you to see who is providing relevant content. Follow them!
• Check which accounts the organizations involved in your key issue follow.
Why does it matter?

• More followers can **exponentially expand your reach** when they retweet you or share your posts on Facebook.

• **More followers = more people to potentially take action** (such as contacting elected officials with a specific ask) or to share information (such as a new report, infographic or favorable news coverage).
Become a Reliable Resource

• **Ask Whether It’s Useful:** Will a tweet be interesting or helpful to your intended audience?

• **Quality over Quantity:** Quality trumps quantity.

• **Avoid Spam:** Tweeting the same message repeatedly in a brief timeframe can cause you to lose followers, or they can mute you so they no longer see your tweets.

• **Extend Your Reach:** Use common hashtags (especially #RareDisease).

• **Have Conversations:** Twitter isn’t a one-way street; the opportunities to engage patients, researchers, bloggers and reporters are vast.
Engage Policymakers

• Twitter is a great way to engage policymakers.
• Thank them by using their official Twitter handle for a vote, meeting or even a thoughtful response to an inquiry. Include a photo of the meeting if you have one.
• Engage in discussions about legislative initiatives such as 21st Century Cures (#Cures2015 & #CuresNow).

Hey @marcorubio & @SenBillNelson, I want to see you vote to support the Florida RareDisease community! #Cures2015

#WRDD2016 @MPSSociety thank you Senator Feinstein for hearing our rare disease legislation
Promote Articles and Blogposts

- You can drive traffic to a blog by sharing posts on Twitter with relevant hashtags.
- You can raise the visibility of your newsletters or articles that advance your policy priorities by tweeting them.

CureTheProcess
@curetheprocess

We agree w/ @WashingtonPost on increased $$ for @NIH: Biomedical research must be seen as a long-term investment ow.ly/WnBnH

SavingCase & Friends
@savingcase

When the cost of your son's medication could buy a new house... every year. bit.ly/SixMillionSon cc @GlobalGenes @RareDR @RareAdvocates

6 Thoughts on having a Six Million Dollar Son
How does it feel when the cost of your son's medication could buy a new home... every year?
savingcase.com
Utilize Twitter for Events

• You can follow conferences and other events remotely or share insights from them using the hashtag (such as #RareDC2016 or #2015GGSummit).

• If you’re hosting an event, socialize the official hashtag early and include it in your materials. Include speakers’ Twitter handles to the program to make it easy for the audience to share content.
Join the Conversation: Tweetchats

- Tweetchats offer the opportunity to engage a lot of people at the same time on a specific topic.
- Rare disease tweetchats are important to raise awareness, share information, and brainstorm.
- Inserting the viewpoint of rare disease advocates in tweetchats on other topics is also important (ex: weekly #HCLDR tweetchats).
- You can look for upcoming tweetchats on Symplur.
Ask and Ye Shall Receive

- You are more likely to spur action if you are specific in the ask, whether it is to retweet important information or to join a campaign.

Pls retweet! Applications for travel stipends for #RareDisease Week on Capitol Hill (2/29-3/3/2016) are due Dec 31st
rareadvocates.org/rdw/
Facebook

- Like Twitter, Facebook can be used to:
  - Raise awareness of events, public policy campaigns, and media coverage aligned with your key messages.
  - Spur people to take action, such as calling elected officials and joining public policy campaigns (All I Want for the Holidays is #Cures2015).
  - Strengthen relationships with other organizations by highlighting their resources and public policy campaigns.
  - Drive traffic to your website through promotion of action alerts, newsletters, and other resources.
Facebook Case Study #1

Shira Strongin
Founder of The Sick Chick Network and We Are More

[Image of Facebook profile for Sick Chicks Community]
Facebook Case Study #2

Jeff Leider
President and Founder of Let Them Be Little X2

Let Them Be Little X2 Foundation
Health/Wellness Website

1,742 people like this
Kristine PJ and 16 other friends

Invite friends to like this Page

Write something on this Page...
Resources

- Global Genes recently released a free new toolkit on How to Promote Your Rare Disease Story through Social Media: https://globalgenes.org/toolkits/


- Storify enables you to tell a story with tweets from a tweetchat, conference or hearing, or based on a hashtag. https://storify.com/

- The World Orphan Drug Congress released a list of top social media influencers in rare disease in 2013 and updated it last year.
  - Original: http://www.terrapinn.com/template/Live/documents/7057/16197?#sthash.w95Xzns7.dpbs
  - Update: http://www.orphan-drugs.org/2015/01/29/social-media-rare-disease-community/
Thank you for joining us for #RareDC2016!