RDLA
Rare Disease Legislative Advocates
POWERED BY THE EVERYLIFE FOUNDATION

Rare Disease Advocacy on Social Media

TIP SHEET

Social media is a great tool for engaging with your Members of Congress. Staffers for each Member pay close attention to the social media pages, and many legislators engage on social media themselves as well.

How should I use social media for advocacy?

You can use social media like Facebook and Twitter in a variety of ways to engage with your Members of Congress. Social media can be used to make them aware of problems you and your community face, thank them for actions they have taken (cosponsoring a bill, voting a certain way, etc.), and make them aware of how pieces of legislation would affect you and your community.

What is a hashtag?

On Twitter and Facebook, the pound sign or # turns any word or group of words that directly follow it into a searchable link. This allows you to organize content and track discussion topics based on those keywords. For example, if you want to post about Rare Disease Week on Capitol Hill 2021, you would include #RareDC2021 in your post to join the conversation. You could then click the hashtag to see posts from other people who have used the same hashtag.

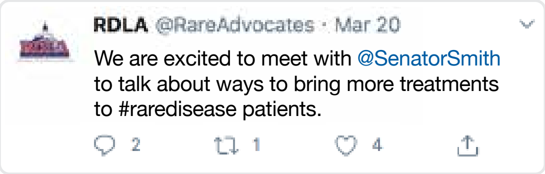
How do I "mention" someone on Twitter?

- ★ Many Members of Congress and Congressional offices have Twitter accounts to interact with constituents. If you know your Member's Twitter name, you can @mention them in your post. For example, "@SenatorSmith"
- ★ If you don't know your Member's Twitter name, check his or her official website.

If you are meeting with your legislator in person, you can highlight your meeting on social media.

1 BEFORE THE MEETING

Create a post tagging the Member's office and the issue you will be talking about.



RDLA @RareAdvocates · Mar 20

We are excited to meet with @SenatorSmith to talk about ways to bring more treatments to #raredisease patients.

2 DURING THE MEETING

Ask to take a photo at the end of the meeting. Take notes during the meeting so you can include key information or good quotes in your posts about the meeting.

3 AFTER THE MEETING

Post your picture with the Member or their staffer with a thank you on Twitter and Facebook emphasizing the key point discussed during the meeting.

RDLA @RareAdvocates · Mar 20

Thank you @SenatorSmith for supporting legislation to bring more treatments to #raredisease patients.

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state and federal policy makers. For additional assistance, please contact Shannon von Felden, RDLA Program Director, at svonfelden@everylifefoundation.org.

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