



HOW TO PROMOTE YOUR RARE DISEASE STORY THROUGH SOCIAL MEDIA

HOW TO PROMOTE YOUR RARE DISEASE STORY THROUGH SOCIAL MEDIA



Introduction

Most rare diseases are not well understood, do not have a cure, and have limited treatment options available. Therefore, living with a rare disease is an ongoing learning experience for many patients and their families.

By telling a personal story, you can help shed light on a condition's symptoms, prognosis, and other details for those still searching for the correct diagnosis and help to raise awareness. Personal stories frame our individual rare experiences in a way that lets us better connect. To learn more about why rare disease stories matter and how to put together a story, turn to the **Using Storytelling to Raise Awareness for Your Rare Disease toolkit** (<http://globalgenes.org/toolkits/storytelling/why/>).

This toolkit complements our **Using Storytelling** title but goes one step further by helping storytellers bring greater awareness to their personal journeys by taking advantage of social media. This Toolkit focuses on the value, use, and practical application of social media to promote our stories.

What is Social Media?

Social media is a term being tossed around a lot lately, but what exactly is it? The best way to define social media is to break it down. **Media** is communication channels through which news, entertainment, education, data, or promotional messages are disseminated. So social media would essentially be a social channel of communication.

The channel doesn't just give you information, but interacts with you while giving you that information. A couple of examples of interactions are:

- Sharing information you find relevant;
- Asking for comments;
- Letting users vote on a campaign; and
- Allowing contributors to build an online information source.

Think of traditional media as a one-way street where you can read a newspaper or listen to a report on television, but you have very limited ability to provide feedback. Social media, on the other hand, is a multi-lane highway that gives you the ability to communicate back and forth.

This short animation *Paradigm-shift in information flow* (<https://www.youtube.com/watch?v=rFWVCFXdTMo>) is narrated by e-Patient Dave (@ePatientDave) and introduces ideas presented by Lucien Engelen (@lucienengelen). It will help you to visualize how the changing flow of information is changing health care as patients are more engaged.

SECTION 1:

STARTING TO USE SOCIAL MEDIA



"I use social media to connect with other rare disease advocates, promote resources, raise awareness of rare diseases, and inject a rare disease patient perspective into broader online conversations." - Stephanie D. Fischer, rare disease patient and Senior Director, Patient Engagement and Communications at EveryLife Foundation for Rare Diseases

For those who can't exist without social media, using social media to tell your rare disease story may just be a natural extension to your participation. However, you may feel that you already spend too much time glued to a screen and that having a rare disease is a private issue and social media may seem far too public a venue for discussing one's personal health.

If you're not on social media, and you've already had success sharing your story without it, you may be asking, "*Why begin now?*" Perhaps you've had the misfortune of accessing information about your disease on the Internet that was not overly useful, or you have set up a number of social media accounts but don't know how to get going. Regardless of why you are reluctant, it's never too late to investigate social media and to decide for yourself if it's a good fit for you.

Following are examples of how to use different social media platforms to convey and share your rare story in three different messages.

Facebook:



Instagram:



Twitter:



SECTION 1: STARTING TO USE SOCIAL MEDIA

“I turned to Facebook in a last ditch attempt to find anyone who knew anything about this disease. There are now over 1,800 members in our support group and collectively, we house the world’s knowledge on this disease.” - Corrie Painter, Angiosarcoma rare cancer survivor and Vice President of Angiosarcoma Awareness, Inc. (www.cureasc.org)

Is Social Media Worth My Time? Should I be Worried about My Privacy?

In the rare community, often the goal is to raise awareness with as many people as possible and/or connect with others that have information about the disease and are going through similar challenges to build a network of support. The number of people worldwide that are engaged in social media is huge and growing! (Statistic links can be found in the **Resource Guide**)

General Social Media

- Globally, there are over 3 billion Internet users.
- Nearly 2.1 billion people have social media accounts

Facebook

- Facebook (FB) adds half a million new users everyday, six new profiles every second
- There are 1.4 billion Facebook users
- 70% of users view FB daily

Twitter

- There are 284 million active users
- An average of 500 million tweets occur per day

Instagram

- Over 300 million users
- 53% of users are under the age of 30 (this channel is valued the most among the youth population)

YouTube

- 1 billion people use YouTube every month
- We watch over 6 billion hours of video on YouTube per month
- 400 hours of video is uploaded every minute

Although the statistics provided represent the four leading social media platforms this Toolkit will examine in detail, social media is not limited to these examples. A large and growing variety of platforms exist that also should be considered as a way to share your story, such as: LinkedIn, Pinterest, Google+, Tumblr, and countless blogging platforms.

While there’s nothing wrong with being cautious about using social media, if you don’t have a massive marketing budget at your disposal and your rare disease is not commonly known, social media can offer an inexpensive way to reach a limitless global audience. If you think your story is important to share or you are looking to connect with others with a similar story, you should seek out a way to take advantage of this incredible communication potential.

The Mayo Clinic’s YouTube channel (<https://www.youtube.com/user/mayoclinic/featured>) shows *How Social Media Is Helping Hearts* (<https://www.youtube.com/watch?v=sPm58WS8b1g>), one couple’s video story of why it’s never too late in life to get on the Internet, in search of answers after receiving a rare disease diagnosis.

Not only can you contribute your individual experiences to discussions, but by interacting on social media, you will naturally connect with valuable new disease information and supports. Also the more you participate, the more you’ll develop the skills to decode the information available and be better equipped to assess the validity of materials coming from various sources.

“I think the best application of social media among rare disease advocates is not simply raising awareness, but in providing a community for those affected by rare diseases. Raising awareness is important, but I think providing a safe place for those

SECTION 1: STARTING TO USE SOCIAL MEDIA

affected by rare diseases to talk with one another, share stories, and ask questions is one of the best uses of social media.” - Kevin Alexander, Filmmaker and Producer of PKULife.tv (<http://www.pkulife.tv/>)

This type of learning and connecting is critical to e-patients. Many people think that the popular term e-patients means “electronic patient,” partially because of a strong Internet presence by self designated e-patients, but in fact, it has more to do with being engaged in your own health than simply being online. That said, there is no doubt that social media is playing a vital role in supporting the current trend towards participatory health, where patients are equal partners in their care. Search online using keywords like **e-patient** and **participatory health** for more information on the role of patients as partners and the use of technology for this growing movement.

Naturally, to take advantage of social media, you have to be willing to put yourself out there and interact with others. But all the major platforms offer supports and privacy settings that can help you manage how public you want to be in sharing your rare disease story. Read up on your **privacy options** before setting up an account, so that you know what you are getting into and can turn on your desired settings from the start. You can also review the short “Smart Social Networking and Communication Tips” (<http://www.gcflearnfree.org/internetsafety/7.5>) for **Internet safety** from GCFLearnFree.org (<http://www.gcflearnfree.org/>).

Consider seeking out online support networks specifically for rare disease patients where registration may be required and discussion moderated. Two examples of these are PatientsLikeMe (<https://www.patientslikeme.com/>) and RareConnect (<https://www.rareconnect.org/en>).

Even with various privacy settings and restricted access groups, you should always be aware, that what you post has the potential to be seen by someone you don’t want seeing it—information can easily be leaked. If it’s not something you’d feel comfortable sharing in person with acquaintances, colleagues, or strangers, you should be thoughtful about sharing it on social media. When in doubt, leave it out, at least until you’ve had a chance to think about it.

The snappy video **#SocialAtMayo** – Mayo Clinic’s Social Media Guidelines (<https://www.youtube.com/watch?v=pjocDhlicJs>) reminds us that healthcare professionals are also having to think carefully about what’s appropriate for social media and learning new skills for engaging online. See if you can pick-up any relevant tips from this video for your own use.

Ask Yourself:

1. What are my privacy concerns when it comes to social media?
2. How public am I willing to go with my rare disease story and what are my individual limits for what I want to share through social media?
3. Do the potential benefits of participation in a particular online community outweigh the risks to the confidentiality of my personal health information?
4. What options do I have to protect my privacy and what can I do to contribute to a supportive social media environment for the rare disease community?

SECTION 1: STARTING TO USE SOCIAL MEDIA

Determining Your Social Media Goals

“Parents and patients have of course always been passionate about finding answers and raising awareness for their particular rare disease. They finally now have a strong platform for distributing their messages—loudly and swiftly—through social media and the Internet. It’s given them a much better way to connect as a community, and as importantly, has put faces, voices, and stories in front of a global audience.”
- Michelle Berg, Vice President of Patient Advocacy at Abeona Therapeutics speaking on RARECast (<https://globalgenes.org/raredaily/rarecast-addressing-life-threatening-rare-diseases-with-gene-therapy/>).

Social media is powerful because of the open and instant interaction between people that it provides. This means that stories can take off even while you sleep. Exciting for some, this may lead our stories into unexpected (and sometimes unwanted) directions. Because it is always better to be prepared, establishing your social media goals is an important place to begin.

You may join social media just because everyone else seems to be on it, but to get results from your participation you will need to first consider your personal goals. Decide for yourself why social media is the right outlet to tell your rare disease story. This may be different from why and how you use social media in other aspects of your life. Social media might simply be a convenient option to keep those closest to you, friends and family, up to date on your health. It can also be a way to seek out and interact with people with whom you share a similar rare disease experience.

You can further decide to use social media to engage more broadly with the rare disease community and even with people who may

not yet care about rare diseases. There is no right or wrong scope to your interaction, it’s all about what you’re looking to get out of it at the moment. Do you want to learn, to contribute, or to advocate for a change? Knowing what you’re after can help you decide how private or public you need to be.

“If you’re going to put your story out there, do it for a reason and then identify that reason so that the reader can take action. If you’re hosting a fundraiser, link to where people can donate, if you want them to discuss the issue with their friends—make sure there is a page online that shares all the relevant facts. If a petition needs to be signed or representatives need to be lobbied—make the call-to-action clear and identifiable.” - Ilana Jacqueline, Managing Editor of the RAREDaily at Global Genes

A good place to start is considering the **audience** you want to reach, most likely this should include people who already are part of your network. Once you have your intended audience in mind, think about how this audience already is using social media. You’ll want to be where they already are and sharing in a way that is already familiar to them.

Review the **Health Fact Sheet** from the Pew Research Center (<http://www.pewinternet.org/fact-sheets/health-fact-sheet/>) to learn more about how people are currently using the **Internet for health**.

If you’re unsure what your planned audience is doing, take the time to do a bit of research to quickly pick up on the trends of a particular community. Ask people you know about their experiences with social media and for any tips they’d be willing to share. Search online and even sign up to a network to listen in. Identify for yourself a few individuals or groups you think are using social media with success and pick up on what they’re doing.

SECTION 1: STARTING TO USE SOCIAL MEDIA

“Not sure which audience to target? Target the category that you belong to. Chances are good you already speak their language, and speaking the right language enables you to connect to people that you’ve never met before.” - Benjamin Von Wong, maker of the #SavingEliza viral video (<https://www.gofundme.com/ElizaONeill>).

Ask Yourself:

1. Why am I using social media?
2. Who do I want to communicate with, and what should I be doing to best connect with this audience?
3. How important is social media to getting my rare disease story out, and how much time/energy will I invest?

Ensuring a Consistent Social Media Message

Social media has given us a platform to broadcast personal messages to accomplish certain goals. For professional purposes, we have LinkedIn to connect with others in our industry and field. For sharing with friends and family, there’s Facebook. Pinterest is where we find and foster our passions, while Instagram is for visual self-expression. And Twitter, for some people, can be for all of the above.

“We’re all storytellers. We’re all journalists and novelists of our own lives and relationships. Twitter, Instagram, and blogging are modern ways of saying ‘Here’s what’s happening in my life.’” - Brian Grazer, Hollywood film producer, *A Curious Mind: The Secret to a Bigger Life*

It is good, for those just starting to engage on social media, to realize that how you present reflects your personal “brand” (brands aren’t exclusive to companies). Think of a **personal brand** like a person’s reputation. It refers

to the way other people see someone as a representative of an idea, organization, or activity. Are you a rare disease patient advocate? Are you trustworthy? What do you stand for? Who are you connected to? What does someone think when they hear your name?

Your brand doesn’t just come into play with social media but it may get increased visibility through social media. Social media is your tool, so make sure interactions reflect you. Ensure you’re recognizable to the people who already know you. For example, if you’re using a website or blog already, try to establish a similar look so your audience makes the right connection. If you don’t yet have an online presence, think about the first introduction you want to make and get started. Include your social media links in all of the places people are used to finding you and be sure to announce a new social media presence.

Healthcare social Media Consultant, Marie Ennis-O’Connor has shared the slide presentation *Six Steps To A Simple Social Media Strategy* (<https://www.linkedin.com/grp/post/4048287-6014822650013114369>). You don’t need to be running a business to take advantage of the advice.

Ask Yourself:

1. What reputation have I built already, and how do I want this reflected on social media?
2. How do I make myself easily recognizable on social media?
3. Am I representing myself or a particular group, and how do I clearly indicate my position?

SECTION 1: STARTING TO USE SOCIAL MEDIA

Consider how to use each channel to accomplish goals, both personally and professionally, to help cultivate a personal brand. And remember, some content may be appropriate for all channels, while some may not. In fact, you may decide not to use all available channels. Think ahead and act consistently when uploading pictures, writing posts, and reacting to others. Here are five things to keep in mind:

- **Be Transparent.** Build trust by making it clear where your perspective comes from and what your stake in the discussion is (why you are sharing your story). Let your audience know if you're speaking as a patient, a parent, a caregiver or a representative of an organization.
- **Get Visual.** They say a picture is worth a thousand words, and nothing is truer than on social media. Social media tracking from BuzzSumo (<http://buzzsumo.com/>) shows that, "having at least one image in your post leads to more Facebook and Twitter shares." Pictures say volumes about a personal story, so prioritize building up your own photo library so that you can better illustrate your individual story.
- **React in a Timely Manner.** Even if you can't always be online, your audience is counting on you to participate at regular intervals and to be responsive, especially to what's happening around you on social media. Make sure to take the time to acknowledge your audience by responding to comments, answering questions, and saying thank you often to supporters.

- **Read Twice and Update Often.** Every post contributes to people's perceptions of your story. Always post carefully and never in too much haste. Posts can be taken out of context, and you never fully predict what others will do with what you share. You can sometimes update your content at a later time if need be. You can also post a response if you feel you've been misunderstood. Don't wait to set the record straight.

- **Remember to be Consistent.** One of the most important components of a great brand and story is consistency. Consistency doesn't mean becoming a broken record but rather always acting with sincerity and showing off your best self.

Watch *Let's Get Started! with Social Media* (<https://drive.google.com/file/d/0B2Ca00TjC3CpUVhTMWlpMHhUV2M/view?usp=sharing>) from Melissa Hogan during the Conversations with the Experts, 2013 Rare Patient Advocacy Summit. The full presentation is available here: <https://vimeo.com/75931727>

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



Keep in mind that even if you post the most interesting content, it won't really matter on social media if no one is paying attention. Social media is a very busy place, and you may need to help your audience find you. The more people that see your content, the better.

Being Part of the Social Media Community

If you want others to engage with your content—to comment on it, share it, or link to it—you'll need to be doing the same with theirs. For social media to be effective, you have to get used to being in a position of both leading and following. This means becoming a **trusted social media contributor**, someone who participates with regularity and authenticity, brings new information to the network, and pays attention and acknowledges what others are providing.

“Creating solid relationships and building a social media following takes time and dedication. It's a continuous process, but it's worth it. If you're just starting out on a new social media platform, begin by connecting with people you already know or people that you communicate with through other social media accounts.” - Emily Ladau, Disability Rights Advocate and Owner of Social Justice Media Services

Also use the platform's search bar to look for new people of interest to connect with and follow. To get a diverse rare disease perspective, intentionally seek out a variety

of community members, including scientists, regulators, and the pharmaceutical/biotech industry members.

“We tend to ‘preach to our own choir.’ There are many communities that ‘overlap’ with the rare community. These communities are generally very interested in and receptive to hearing what transpires in the rare community; however, most often, they miss our messages.” - Yonatan Maisel, Rare Disease Patient and Advocate

Showing interest in others, including common social media behaviors such as liking, following, friending, and subscribing, is the easiest way to generate your own audience, as many people will reciprocate a positive interaction.

Standing Out as a Rare Disease Advocate

If you're setting up a new account, think about the name(s) you will use. Which name will be part of your public profile? Should it match up with existing parts of your personal brand or is it an identifiable nickname exclusive to social media or a particular channel? Before committing, check for existing similar names that may create unwanted confusion. You can also **use a username generating tool** like SpinXO (<http://www.spinxo.com/>) to explore your options.

To introduce yourself and attract followers, always take advantage of the options to **personalize your profile settings**, by adding your own profile image, biography/description and relevant website links. Be sure to provide a taste of both how you are unique and how you connect with others. For example, you may want to identify a specific disease you are connected to but also mention your rare disease community membership, and perhaps more broadly, your commitment to health issues or a subsection of health, such as lung disease. Include links that can help

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY

people learn more about the issues closest to your heart. Your profile should also reflect the position you are speaking from and what you contribute about.

Visit the channel specific help center for tips on creating a professional look for your account, including important image size specifications. Keep in mind that while you want to maintain a consistent look, not all images (including logos) will work well on all channel platforms and dimensions may need to be adjusted to better suit their use. The Ultimate Guide to Using Images in Social Media (<http://www.jeffbullas.com/2014/06/23/the-ultimate-guide-to-using-images-in-social-media/>) provides useful tips of this nature. Often you'll have the option to edit images after you upload, but sometimes it can be better to do this with image editing software beforehand. Techlicious (<http://www.techlicious.com/guide/best-photo-sharing-sites/>) recommends Photobucket (<http://www.photobucket.com/>) as a great tool for photo editing.

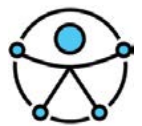
For larger awareness days and campaigns, such as World Rare Disease Day, look to organizing groups for promotional materials specifically created for social media use, such as **profile or cover images**. Contributing to these types of campaigns helps spread a united message for the cause, makes you easily recognizable as an advocate, and harnesses the power of social media.

For great ideas on using social media for World Rare Disease Day (annual event held on the last day in February) watch:

- *RARE Webinar: World Rare Disease Day 2016 Planning* presented by Global Genes (<https://globalgenes.org/wrddplanning2016/>)
- *Maximising Social Media around Rare Disease Day* presented by RareConnect, EURORDIS (<http://www.rarediseaseday.org/page/news/maximising-social-media-around-rare-disease-day>)

You don't have to be a professional designer or writer to improve your appearance, but always preview before saving changes. Be sure to check your social media appearance using different browsers, such as Internet Explorer, Firefox, and Chrome. See how you look using various screen sizes on different types of computers, including desktops, laptops, and mobile devices. Keep in mind the technology most commonly being used by your audience and stay tune for ongoing changes.

Since we want our stories to reach people, improving accessibility should always be up for consideration. Be aware that any verification tools you may put in place to verify that users are real people, may in fact be keeping people out. Try before you apply. It's also courteous to double check that any of the web links you include actually work and aren't misleading. Find the language that's clear and understandable to your audience. Be open to accessibility ideas, such as exploring translation, sound recordings, and the use of visual representations, such as infographics. Read up on 5 Ways to Ensure Your Site Is Accessible to the Visually Impaired (<http://mashable.com/2011/04/20/design-for-visually-impaired/#z749A4ly4Pq6>) and ask your audience for input.



Samples of social media resources from Global Genes to unite and promote messages about World Rare Disease Day

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY

Standing out as an advocate goes beyond cover appearances though. Each of us has a lot to present, but it does not need to be a one-sided presentation. Besides posting your own information and opinions, be sure to invest equally into finding out what other advocates are communicating on social media. Show your genuine commitment to the rare disease community by asking questions, commenting, and lending your support to important community initiatives.

Social media is the place to connect around shared experiences but also an opportunity to learn more about the important differences that make up our community. Use social media to strengthen your voice and build greater rare disease sensitivity and awareness.

Ask Yourself:

- What's my role as a leader and as a follower on social media?
- Who am I paying attention to and who's paying attention to me?
- What can I do to attract the interest and support I want to get from social media?
- How do I make what I'm sharing more accessible to my audience?

Tips for Using Facebook, Twitter, YouTube, and Instagram

As mentioned in the previous section, some content may be appropriate for all channels, while some may not. The various channels allow users to connect without geographic boundaries with other patients, the wider rare disease community, and far beyond. This section will break down the dos and don'ts of four popular spaces being used by the rare disease community, Facebook, Twitter, YouTube and Instagram.

For all the channels, there is a lot to gain from visiting their official help center, especially when first joining. The help centers aren't just useful for solving technical problems, they also offer excellent advice on how to be successful using the platform. Find the help centers here:

[Facebook Help Center](#)
[Twitter Help Center](#)
[YouTube Help Center](#)
[Instagram Help Center](#)

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



FACEBOOK

Facebook is the world's largest social network and a growing source of health information. Originally the focus was around connecting with friends and family, but today it's grown to include all aspects of our society, including organizations and special interests.

Individuals have **profiles** on Facebook while larger entities such as companies, organizations and campaigns have official **pages**. Unlike an individual's profile, pages are automatically public, allowing anyone on the internet to access the information. For smaller entities you have **Facebook Groups**, which let people with common interests interact. Groups can be public (available for anyone to join), require approval for joining or be by invitation only. The Gaucher Disease Facebook Group, for example, is a private group started by Cynthia Frank and another Gaucher patient.

"The people who join can feel confident that they are sharing their stories with like-minded people, looking to connect with others from within the community. It serves the same purpose as an in-person support group, except that it is online. While a group and a page serve very different purposes, I see both to be important to the health of our

community. Having varied opportunities to connect can help overcome the feelings of fear and isolation which are often present in dealing with a rare disease." - Cynthia Frank, Gaucher Patient and Rare Disease Patient Advocate

Separate from this private group, the National Gaucher Foundation, Inc. (NGF) in the United States has a public page (<https://www.facebook.com/pages/National-Gaucher-Foundation/333921202263>) used by the organization to disseminate trusted current information on Gaucher, rare disease news, and events.

Facebook's popularity comes from the ability to easily communicate with all the people and entities you care about at the same time. Facebook is used to organize and share different types of information about you and your interests. It's a place to post heartwarming photos, videos, interesting articles, updates on your daily life and the issues that matter to you.

Just starting out on Facebook? Here are some key things to know

Profile pictures and **cover photos** can be photos taken by smartphones, tablets or cameras and uploaded to represent your personal brand or organization and be used for promotion. **Profile pictures** will appear as your thumbnail when being searched. This can be an individual photo or be changed to show a logo, event, or awareness day. The **cover photo** is like a banner for your personal page. Uploading a photo of your organization's logo or promoting an event is a great use of the cover photo.

To connect with other Facebook users, you need to send a **friend request**, this will allow you to message them, post of their wall, and tag them. Similarly, you can **like** pages or you can join groups based on your interests. By



Example of a Facebook Profile: National Gaucher Foundation, Inc. (United States) (<https://www.facebook.com/pages/National-Gaucher-Foundation/333921202263>)

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY

friending an individual, liking a page or joining a group you will be able to post comments on their home page **wall**. These posts are viewable to the public. Likewise, they are able to post on your personal wall. This is a great way to share links, articles, videos, etc. with other people and groups/organizations.

On your Facebook homepage, you can **update your status**. Here you can share your thoughts, links, photos, videos and articles (think of it like twitter on Facebook) and it will appear on your friends newsfeeds (you can change the security settings to limit who can see what!).

In order to get the attention of an individual, organization or group, you can tag them in a wall post or status. This will send them a notification. Likewise, anything you post or post on, if there is a reply or comment to it, you will be notified of the activity.

Newsfeed appears on your homepage when you first login. This will show posts and statuses of friends and groups you are connected to. Facebook can be linked to many of your other social media accounts, utilize this feature by linking your Instagram, YouTube channel, and Twitter account to Facebook, so everything you do on the other platforms will automatically appear on Facebook. But don't forget to provide links to your other accounts on Facebook too.

Engagement on Facebook is what determines how many people will get to see what you share. For the purposes of Facebook, engagement is measured by number of **likes, shares, clicks, and comments**. Having people read your story won't help spread it if they don't follow through with one of the above actions.

Following are some more tips for Facebook

- To share the appropriate story, know where you are on Facebook. Are you sharing with friends, in the context of a private group, or as the representative of an organization with a public page?
- Get to know your Facebook community so that you can best **target your audience**. As an individual on Facebook, you can choose each time you share, which audience you want to connect with. Are you going to go public, just to friends or create a custom list for your post? Being able to reach-out to a specific audience means you can mold your story for your audience.
- Keep it front of mind, that no matter how serious your story is, people use Facebook to be entertained. If you can find a way to make what you share on this channel relevant, useful, and fun, you'll have a better chance of getting people to engage.
- As a storyteller on Facebook, two things you should always strive for are to keep text as short as possible and use eye catching, good quality photos.
- Create easy ways to encourage engagement by sharing an inspiring quote, offering a relevant tip, asking an interesting question or starting a fill in the blank.
- Pay attention to what's trending, so that you can respond spontaneously with your own twist. You don't need to repeat what's in the news, but instead experiment using what's current to tell your own story and relate to more people. Check Google Trends (<https://www.google.com/trends/>) to find the latest topics.

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY

“I believe that people need to understand that a person isn’t a disease. When I started being active on Twitter, I really struggled deciding whether I should just stick to the ‘rare disease stuff’ and advocacy. But really, I bring my whole self, my nerdiness, my feminism, and the ups and downs of parenting. It’s the whole picture and it all plays together.” - Isabel Jordan, Chair of Rare Disease Foundation and Patient Advocate



TWITTER

Twitter is all about short messages, or **tweets**. Tweets can include images or video, but a strong emphasis on snappy text remains (restricted to 140 characters per tweet, including links).

Just starting out on Twitter? Here are some key things to know

Your homepage timeline is a great way to source customized rare disease information and stories. Similarly to Facebook, you want to connect with others. In Twitter you have followers or you follow others instead of “friend.” You can often search to find people and relevant organizations.



Example of a Twitter Profile: Isabel Jordan, Chair of the Rare Disease Foundation (@seastarbatita)

When you notice an interesting tweet, you can share it with your followers by hitting the **retweet** button. You will also have the option of adding a comment before retweeting and this is a way to personalize what you are sharing, so that

your followers can see why you think the information might be relevant to them. The person and/or organization that you retweet will get a notification that you did and will often “follow” you back if they weren’t already. It’s a great way to build your network and reach. The ultimate goal is to build the number of people and organizations that are following you and get them to retweet your content to their followers and so on. The more people that share your tweets the better and more reach and impact you get.

You can also share your thoughts by **replying** directly to a tweet. By replying, your tweet will be connected to the original tweet and this may help get your perspective noticed in different circles.

Following are some more tips for Twitter

- Engage with people to get more out of this social network and build connections. The Patient Advocates On Twitter Listly (<http://list.ly/list/4V0-patient-advocates-on-twitter>), compiled by Healthcare Social Media Consultant Marie Ennis-O'Connor, is a helpful place to start looking for contacts.
- Maximize the limited characters permitted in a tweet by using **abbreviations** and free **URL shorteners** when including links. You aren’t obliged to use all the Twitter lingo, and at times the best way to stand out is to intentionally not.
- **Photos** have become a critical part of Twitter communication. Keep in mind that photos will mainly be viewed by your followers on their timeline. Regardless of the image shape you are able to upload, it will appear as a rectangle on the timeline and be scaled where necessary. Viewers will have the option to click to view the full photo but you can improve immediate visibility by becoming aware of the image sizes that show up best. Look to the help center for specifications but most importantly, look

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



for yourself how your images appear on the timeline and keep this in mind when selecting images or cropping.

- Use **hashtags**!
 - Research and make a list of **hashtags** to use in your own tweets. Hashtags use the # symbol at the beginning and are simply a tool to make words more searchable and allow Twitter users to tap into a Twitter-wide conversation.
 - Take advantage of the hashtags that are already being well used, such as #raredisease. Follow what **healthcare leaders** are saying on Twitter with the #HCLDR hashtag.
 - When you are signed into your Twitter account, you can also get customized updates on the hashtag **trends** to follow and take advantage of in your own tweets.
 - To create a new hashtag, place # before a word or series of words without any spaces. Creative hashtags are one way to get noticed on this channel.
 - Direct your message to your audience by using the right hashtags and keywords. Keep in mind that there are many communities that overlap with the rare community, including ePatient, cancer, genetics, genomics, data, bioinformatics, pharma/biotech, scientists, and researchers. Target your tweet message without overly limiting your potential audience.
- Join a rare disease **Twitter chat**, also referred to as a **tweet chat**. This is a live discussion event where people communicate on a particular topic, using a chat specific hashtag. These events are often led by a moderator, who helps guide the discussion with an agenda and key questions. Look out for chats around advocacy campaigns, awareness days or special events, hosted by rare disease organizations.
- If you are attending a conference or special event, take advantage of the “15 Tips For Tweeting A Live Event” (<https://www.linkedin.com/pulse/20141107102756-35897939-15-juicy-tips-for-live-tweeting-an-event>) offered by Healthcare Social Media Consultant, Marie Ennis-O’Connor.
- Use the **direct messaging** feature to send a private message to any of your followers. This can be a good way to ask trusted followers for support getting a specific announcement out on Twitter, or for their participation/input on a project. Direct messaging is more effective when used sparingly and for making a logical request of a follower.

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



YOUTUBE

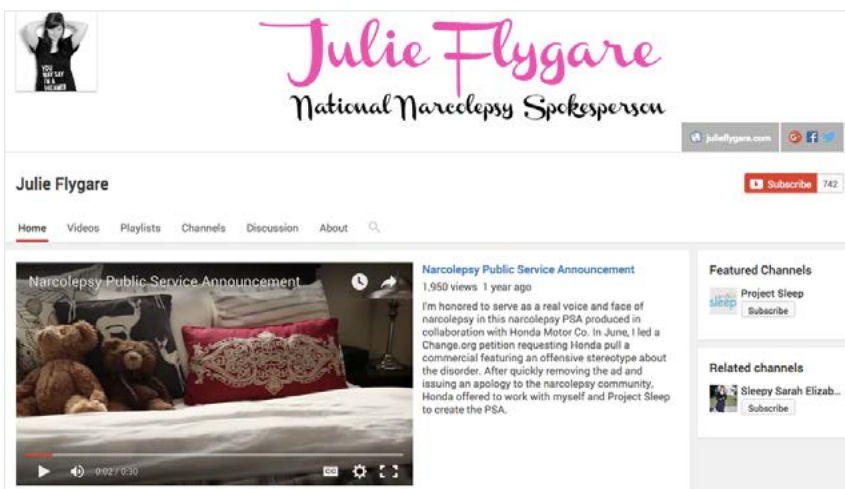
A video-sharing website, YouTube may not be the first thing that comes to mind when one thinks of “social media.” But don’t be quick to rebuff; this channel may be a good fit for helping share your story.

Just starting out on YouTube? Here are some key things to know

To upload a video you’ll set up a personal **YouTube channel**. Your channel allows you to showcase all your videos in one place and to provide your audience with further information about who you are and the types of video stories they can expect from you. YouTube channels are set-up with a Google account. When starting to use YouTube consider if you want to connect with an existing account you own or if it would be preferable to start a fresh one. When you **upload a new video to YouTube**, set it to private until you’re ready to go with key information such as a title and video description.

Following are some more tips for YouTube

- Take advantage of the option to show a **channel trailer**, a featured video that introduces new viewers to your channel. When picking what to use, keep it short and assume that the viewer knows nothing about you/your rare disease. If you don’t have an appropriate option, you can make a video for this purpose or you can edit existing material into a short intro piece.
- YouTube is the place for all **different types of videos** and your channel can be the same. You might have the chance to work with a professional to create a video story, but not all your uploads need to be of this standard. A less fancy piece, using a smartphone for example, can be equally relatable while taking less time and resources to generate. You can also share video footage from events or presentations or provide a video update on an earlier story. Most important is to keep your audience engaged with **new offerings** at regular intervals.
- Don’t make all of your videos long. This can discourage users from watching. If you have a video that is over five minutes, consider making a **preview video** for it, of 60 seconds or less, or breaking the content up into **smaller segments**. Even without technical experience, you can edit existing videos using **YouTube video editor**. When you’re done, you have the option of saving your changes as a new video.
- Editing options also allow you to pick or customize your **video thumbnail**. Video thumbnails are a snapshot frame that appears during a search or is seen before the video starts to play. A clear video thumbnail is critical, as it’s the first impression your video will make. YouTube generates three automatic options that you can select between, or customize your own.



Example of a YouTube channel: Julie Flygare, National Narcolepsy Spokesperson
<https://www.youtube.com/user/jflygare>

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



- Pick the **right title** for your video. Your YouTube video title may in fact need to be different from your original title. Make sure the title is to the point, as descriptive as possible, and uses relevant key words. The title should attract viewers but it should never be misleading.
- Provide a **complete video description**. It's to your advantage to include as much written information as you can here, including links to direct people wanting to find out more. This text helps YouTube rank the video in terms of **keywords**. Make sure to present all relevant search words, especially adding ones not used in your title. The words you identify as important, should also be used as your **video tags**, giving your video the best chance at being found.
- To make your videos accessible to a wider audience, check out the many options, in your YouTube video manager, for adding and editing **subtitles** and **captions**. Subtitles allow your video to be understood by those speaking different languages and captions support hard of hearing or deaf audience members. YouTube often adds automatic captions to videos. You can also create your own, or edit the ones available, to improve accuracy, especially when it comes to medical terminology. This can be a great task to get help from friends and family with. The process is often more time consuming than difficult.
- Your channel video manager also allows you to add **annotations** to your videos, for example a speech bubble or live link. An annotation provides extra content, at a specified time, overlaid on your video during play. There are many available customizations for location, font, color, shape, and size. Annotations allow you to update a video easily and encourage more immediate engagement. For example, add a call to action like "subscribe to my channel now" or a clickable "donate here" link.
- Don't just keep putting up videos on your channel when nothing seems to be happening. Simply putting together an amazing video on your story and uploading it to your YouTube channel will probably not bring the attention you want. Connecting with others in the community will be critical to ensuring your video is actually seen.
- Demonstrate your interest in rare disease stories by **subscribing** to other rare disease related YouTube channels. Your subscriptions will be visible to those visiting your channel and may provide a helpful source of information.
- If you have a number of videos, help visitors navigate your channel by creating **playlists** that appropriately group together your videos by topic. You can also put together playlists made up of other videos on YouTube. For example, these could include videos about a specific rare disease or your favorite rare disease community videos. Thoughtful and selective playlists will be appreciated by your subscribers and regular additions are another way to keep your channel fresh.
- You can share YouTube content while hooking up your other social networking accounts. So as you upload, comment, favorite or like a video, these actions will be broadcast to your Facebook and Twitter accounts for your friends and followers to see.
- Most of the videos on YouTube, that you want to share on your own website or blog, can be **embedded** into your desired web page, so that your audience doesn't have to leave your site to watch.

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



INSTAGRAM

Instagram is a fun and easy, and fairly new (it launched in 2010), way to share photos and now short videos (3-15 seconds) from your smartphone.

You get to build a documentary of your life in snapshots and create visual connections. Being part of Instagram gives others a glimpse into your life story and helps people from diverse backgrounds discover a shared humanity through shared images. Setting up an Instagram account can be a great way to start building your own photo library. You can share your Instagram uploads on your other social networking platforms, currently including Flickr, Facebook, and Twitter. Other attractions are that it's uncomplicated, doesn't require a lot of commitment to enjoy, and tends to be a friendly community.

Note: You have to have a smartphone to use Instagram. Visit www.instagram.com to open your account, set up a profile and **download the app** for your iPhone or Android.

Just starting out on Instagram? Here are some key things to know

You're encouraged to use your own photos and videos on Instagram. Feel free to edit images in the application: use the crop square to choose the exact image, use the filters to create the desired effect, choose what to keep in focus and add some brightness.

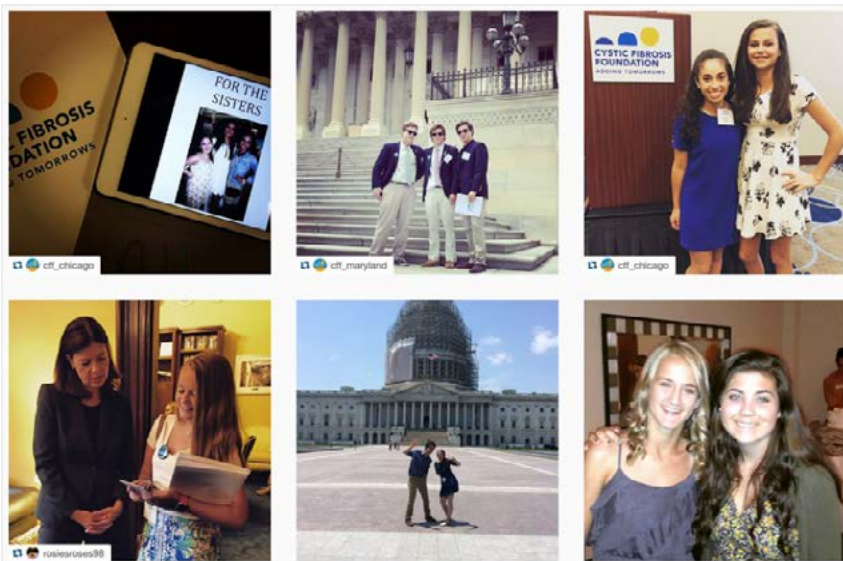
Add a caption. **Captions** bring others into your mind and let them know why you thought it was worth sharing. Any website links you want to include will not be hyperlinked as Instagram is not supposed to be about selling.

Just like Twitter you have **followers** or you **follow** others to see and share content with them. You can often search to find people and relevant organizations. Photos on Instagram are public. You do have a privacy option where people must ask permission to follow you, but it's not widely used within this channel. Once you are following people on Instagram you can like and **comment** on specific photos.

Don't be afraid of using **tags**. Tagging a picture with some of the more widely used tags can connect it with more people, while adding more unique tags may help bring the picture to life. A past example of a popular tag on Instagram was **#RareButReal2015** (<https://instagram.com/explore/tags/rarebutreal2015/>) used for the EURORDIS rare diseases photo contest.

Following are some tips for Instagram

- The "cool" factor on Instagram is the **filters** you can use to modify your photos in neat ways. There are also other **photo manipulation apps** that can be downloaded to give you even more presentation options with Instagram.
- You can also add a **location** to a photo which can be a way for people with interest in the same geographic area to find it.



Example of an Instagram Profile: Cystic Fibrosis Foundation (https://instagram.com/cf_foundation/)

SECTION 2: USING SOCIAL MEDIA EFFECTIVELY



- Like other social media platforms, you can mention other users by including their **Instagram @username** in your comment. Be sure to do this if you want that person to know that you have mentioned them and it's not their photo you are commenting on.
- If a picture touches you in some way that warrants more than a "like," then leave a comment. And if you want to reply to someone else's comment, be sure to use their **@username** so they are notified that a comment has been left for them.
- In general, the more social interaction the better experience for everyone. This does not mean that you have to follow everyone who likes one of your photos, but taking the time to identify images that speak to you, is a great way to find people to connect with. Let the photos be your guide on this visual channel.
- If you want to attract Instagram followers, beyond your network from other channels, use a good **profile picture**, **pick a theme** to focus on, and share interesting photos.
- You may also decide not to overly concern yourself with followers on this channel and rather use Instagram in conjunction with the other channels you are a part of. If this is the case, be sure you are **sharing** your activities on Instagram on your other platforms.
- Instagram has been used to help raise awareness and for fundraising efforts, but it's all about the picture stories to be successful.

SECTION 3: KEEPING THE SOCIAL MEDIA MOMENTUM



Often, people aim for their social media content and stories to go “viral” or something that is shared by a large number of people on a variety of platforms. Despite best practices and efforts, most rare disease stories won’t go viral on social media but that doesn’t mean your social media isn’t successful. Setting up realistic expectations of what progress looks like is important. Most people are unaware of rare disease and often that is incentive enough to continue to share.

Expanding the Life of Your Story

To get your message out, it is going to take numerous tries and some creativity. Don’t abandon your story because it’s not getting the results you had hoped for or you’re afraid your audience may be getting bored. Rather, take advantage of your different channels and the ability to change your story format to keep your audience engaged and to reach new people. If you have a story on one channel, use another channel to direct people there. If you’re not sure how engaged your audience is on social media, don’t forget to keep reaching out with an email message, to let them know of your recent activity online and to provide the appropriate links to connect. Reminders to check back are important, especially at the beginning.

Providing an update to a story can also help keep it current. Your audience will be curious to know what has happened since you first shared your story. Updates can also be a great way to acknowledge supporters publicly and make your audience feel like they are really part of an evolving story. Story updates may coincide with awareness days or special events, respond to comments received or be part of a new call to action. If others are talking about you on social media or you’ve gotten recent news coverage, this can also make for an easy update. An update could be as simple as posting a new photo or a self made thank you video.

“Social media works for storytelling when it has great sound bites, images, and a hook to get people interested (i.e. the ‘how it could have happened to anyone’ aspect), especially if the audience is outside of the rare disease community.” - Melissa Hogan, Founder and President of Saving Case & Friends

Since Eliza’s Sanfilippo video story went viral (<https://youtu.be/G0IY8qG7J-I>) I, the family has kept their Facebook campaign page active, with regular homevideo updates, including this video on Valentine’s Day: <https://www.facebook.com/ElizaOStory/videos/814350771971510/>.

New people may also be interested in hearing what you have to say, they just need a better link to help them relate. Your core story can remain the same but try using different language, a new image, or take a different angle on the story to move outside your immediate community and beyond rare diseases.

SECTION 3: KEEPING THE SOCIAL MEDIA MOMENTUM

Ask Yourself:

- Have I accomplished everything I hoped to by telling my story or is there a reason to keep telling it?
- Am I receiving a lot of similar questions or comments that could be the basis of a story update?
- Can I use a different social media channel to retell or promote my story?
- How can I use social media to reach a new audience with my story?

Evaluating Your Social Media Impact

If your social media channels have some followers and people “like” your content, share your links, and post comments, then you are ready to start measuring your social media impact.

To start, be your own observer. Think back to when you first started and ask yourself, “What’s changed?” What specifically do you see that’s encouraging? Is your participation on social media helping you to share your story?

It’s difficult to keep engaged and grow your social media if it just feels like another chore. To keep momentum, reflect on the amount of time you’ve put into your participation and what you enjoy about being connected through social media. Go back to your original goals for getting started and consider the ways you’re already working towards meeting them and areas you may want to do more.

Once you’re comfortable with your own preliminary examination, it’s time to take advantage of the **tools available for social media monitoring and social media analytics**. Almost all social media platforms provide you with a certain amount of free

data on your account activity. The information can be as basic as the number of views you received, tracked over time, or the number of clicks your content generated. Start looking here and, as you progress, you can sign up for more advanced analysis from a number of different online services. These tools are simply a quantifiable way to identify the actions you are taking and how people are responding but it can be hard to know for sure what impact it has beyond that. The level of detail available can also get overwhelming.

Focus on a few small, positive things you see happening with your social media activity and then investigate why you think it’s working. Is it your timing, your content or your engagement with other people that makes the difference? Make yourself a list of things you think help spread your message and then try them again to see what happens. Keep adjusting based on your observations and the data you track.

“The beauty of technology and social media is that you can try and test different strategies and get pretty much immediate feedback from your community and beyond. So, test new ideas all the time. Try different posting times. Post with images and without. Try posting links and long stories. And listen to the feedback from your followers. When something works, do more of it. When something doesn’t, take note and adjust future campaigns.” - Bill Strong, Founder of Gwendolyn Strong Foundation

SECTION 3: KEEPING THE SOCIAL MEDIA MOMENTUM

Maintaining Your Social Media Outreach

Staying active on social media is crucial for developing and maintaining engaged relationships with your followers. Here are five tips to maintain your social media outreach, so it continues to be successful.

- **Share Useful, Valuable Content:** Don't just promote a presence. Make sure your presence is actually worth following. That means all of your tweets, Facebook posts, and YouTube videos need to add a little something new to the discussion. It doesn't have to be earth shattering news, but always look to make it as relevant, useful, and personal as you can.
- **Interact with Followers/Subscribers:** Acknowledge new contacts. Respond to followers in a timely manner if they've left a comment or asked a question. Reach out to those in your network with a specific request, but make sure it's not always the same ask. People generally want to help and appreciate being offered various ways to take part. Be sure to take the time to thank supporters personally for staying connected and contributing.
- **Advertise your Social Presence:** Use your website, blog, print materials, business cards, or even email signatures to let your contacts know you're on social media. Adding sharing buttons (e.g. "Share on Facebook" or "Tweet This") allows your site visitors and email subscribers to share your content, with their personal networks, in just a click. All the major social media channels offer personalized buttons that you can use without having to understand computer coding. You can also lookup how to create your own button designs.
- **Stay In Touch:** Social media is always changing and growing. Keep expanding your network by looking out for new people to follow and new places to interact. Make a commitment to tune-in, for a designated amount of time on a regular basis, to find out what's happening, to engage in conversations, and to share content.
- **Become a Digital Friend:** You don't have to be a social media expert to support others to get connected. Sharing your experience and skills is a great way to keep engaged, while also helping to build the rare disease social media community. For ideas on giving back, read on about how Digital skills boost the power of community, (<https://socialcare.blog.gov.uk/2015/09/16/digital-skills-boost-the-power-of-community/>) from the UK Department of Health.

Melissa Hogan, Founder and President of Saving Case & Friends, has been able to connect and build relationships with many people through her engagement in social media.

"Without social media, I never would have connected with many advocates in the broader rare disease community, much less other healthcare movements. I started in the Hunter Syndrome community, and the connections have branched out into the rare disease, medical research, pharma industry, patient advocacy, special education, and assistive technology areas. In many cases, we've only 'met' online, but we support each other's agendas, email, and try to eventually connect live at conferences." - Melissa Hogan

KEY TAKEAWAYS



Section 1 Key Takeaways

1. By sharing your story on social media, you are allowing people to take a look at your world. Before sharing your story, know how much you are willing to let people see.
2. Social media is useful for all different reasons. Know what you want to get out of social media and the channel you are using.
3. Social media is like an electronic calling card today. Make sure you stay consistent across all channels, and think of these channels as your personal brand. Determine how you want others to see you and your story.

Section 2 Key Takeaways

1. Social media is a two-way relationship. If you want to get supporters and an audience, check out other stories, pages and groups and leave a comment or follow them. This increases the likelihood that they will follow or comment back on your story or cause.
2. Social media is an outlet for you to be unique. Consider your brand, and don't be afraid to be different from other stories out there.
3. Share the love. If you know of other rare organizations or stories, promote their profiles or links. Remember, you're all still part of the Rare Disease Community.

Section 3 Key Takeaway

1. Keep your audience involved. Provide updates and replies at a consistent pace.

RESOURCE GUIDE



Case for Using Social Media

“Advancing the Science of Patient Input” prepared by FasterCures (https://www.youtube.com/watch?v=Zsn_9EplBz8): Animated digital story illustrates the history of patient involvement in medical progress starting in 1938 until today. This includes a look at how the technologies that connect and empower patient communities have helped to progress the role of patients in research and development.

“How Social Media Is Helping Hearts” from the Mayo Clinic’s YouTube channel (<https://www.youtube.com/watch?v=sPm58WS8b1g>): Video shares one couple’s story of why it’s never too late in life to get on the internet to find valuable information and support after receiving a rare disease diagnosis.

“(Narrated) Paradigm-shift in information flow (Engelen Derksen 2010)” (<https://www.youtube.com/watch?v=rfWVCFXdTMo>): This short animation will help you to visualize how the changing flow of information is changing health.

“Rare cancer meets social media” by Corrie Painter (<http://jamforfries.blogspot.ie/2014/11/rare-cancer-meets-social-media.html>): Angiosarcoma survivor details role of Facebook group in connecting and supporting patient community.

“Why Sharing Is the Future of Healthcare” by Susannah Fox (<http://blog.iodine.com/post/116397436543/why-sharing-is-the-future-of-healthcare>): This piece takes a look at the potential benefits to the healthcare system of individuals sharing their medical stories online.

Evaluating Your Social Media Impact

Buzzsumo (<http://buzzsumo.com>): Data on what content is being most shared and who the top influencers for any topic are.

Facebook Insights (<http://www.facebook.com/insights>): Insights are available after 30 people like your page. They allow you to view metrics behind the page.

Symplur Healthcare Hashtag Project (<http://www.symplur.com/healthcare-hashtags/>): This resource details where the healthcare conversations are taking place, who to follow within a disease, and what healthcare topics are trending.

TweetReach (<https://tweetreach.com/about/>): TweetReach provides measurement on the reach of Twitter accounts, brands, campaigns, events and hashtags.

RESOURCE GUIDE



Expanding Your Social Media Outreach

Patient Advocates On Twitter Listly (<http://list.ly/list/4V0-patient-advocates-on-twitter>) compiled by Healthcare Social Media Consultant Marie Ennis-O'Connor: A helpful place to identify potential contacts to connect with on social media to grow your network.

Paper.li (<http://paper.li/>): Paper.li is a tool that pulls together relevant content from across the web, on topics you select, and allows you to offer the compilation to your audience as an online paper. A long standing Paper.li publication from the rare disease community is "OurSpecialChildren #RareDisease News - Paper.li" (<http://paper.li/~publisher/f63e86f0-82e7-012f-25ad-12313d16b843>).

Storify (<https://storify.com/>): Storify is another way to find, collect, and share what people are saying all over the web. Users can curate the most important voices and turn them into new stories. You can see a Storify example from MassBio's Patient Advocacy Summit (<https://storify.com/MassBio/patient-advocacy-summit-2015>).

The Tweeted Times (<http://tweetedtimes.com/>): The Tweeted Times allows you to turn your activities on Twitter into a personalized newspaper to further engage your audience.

Thunderclap (<https://www.thunderclap.it>): Thunderclap is the first-ever "crowd-speaking" platform that helps people be heard by saying something together. It allows a single message to be mass-shared, flash mob-style, so it rises above the noise of your social networks.

Social Media Statistics

LinkedIn: 33 Social Media Facts and Statistics You Should Know in 2015
<https://www.linkedin.com/pulse/33-social-media-facts-statistics-you-should-know-2015-jeff-bullas>

Pew Research Center
<http://www.pewinternet.org/2015/08/19/mobile-messaging-and-social-media-2015/>

Reelseo: 32 Amazing YouTube Facts and Stats to Tweet and Share
<http://www.reelseo.com/youtube-facts-stats-2014/>

Social Media Today: 10 Amazing Social Media Growth Stats from 2015
<http://www.socialmediatoday.com/social-networks/kadie-regan/2015-08-10/10-amazing-social-media-growth-stats-2015>

RESOURCE GUIDE



Telling Good Stories

Awesome Screenshot (<https://www.awesomescreenshot.com/>): An awesome tool for capturing high quality screen shots and adding annotations to your pictures for sharing.

“A Curious Mind: The Secret to a Bigger Life” by Brian Grazer and Charles Fishman (<http://books.simonandschuster.com/A-Curious-Mind/Brian-Grazer/9781476730752>): Insights from the film producer of A Beautiful Mind on using curiosity to tell good stories.

EPAP (European Patient Ambassador Programme) ([http://www.europeanlung.org/en/projects-and-research/projects/european-patient-ambassador-programme-\(epap\)/home](http://www.europeanlung.org/en/projects-and-research/projects/european-patient-ambassador-programme-(epap)/home)): A free online training course to equip patient representatives that includes the working with the media module that provides tips for using social media.

Global Genes’ “Using Storytelling to Raise Awareness for Your Rare Disease” Toolkit (<http://globalgenes.org/toolkits/storytelling/why/>): Many within the rare disease community do not know how great an impact they can have by sharing their story. Telling your story can be difficult, but this toolkit is intended to help you overcome the challenges by offering advice on ways to get started.

RAREDaily’s “Our Stories Do Make a Difference: Rebecca with Noonan Syndrome” (<http://globalgenes.org/raredaily/our-stories-do-make-a-difference-rebecca-with-noonan-syndrome/>): In this piece, the writer shows the power stories can have and how her experience as a mother with a story has set her down an amazing path.

Social Media Today “On Digital Engagement and Icebergs” (<http://www.socialmediatoday.com/social-business/paul-tunnah/2015-09-08/digital-engagement-and-icebergs>): Paul Tunnah makes the case for posting interesting content on social media to connect with your audience. While this article is targeted at the pharma industry, the points covered are thought provoking to anyone engaging on social media around health.

“Storytelling: The Importance of Your Own Stories for Your Social Media Success” (<http://blog.thesocialms.com/storytelling-importance-own-stories-social-media-success/>): A large part of social media success is created by the content. Susanna Gebauer writes that it is the stories that attract an audience, and in this article, she details the questions to ask yourself and how to start a good story.

Techlicious “The Best Photo Sharing Sites” (<http://www.techlicious.com/guide/best-photo-sharing-sites/>): This guide recommends online photo sites that can help you better manage your photos for your social media stories.

RESOURCE GUIDE



TechSoup's Storymaker Resources (<http://www.techsoup.org/community/community-initiatives/storymakers-resources>): TechSoup's digital storytelling resources provide a step-by-step guide from story creation through post-production and marketing.

VonWong's "The Recipe to a Successful Viral Fundraiser" (<http://www.vonwong.com/blog/viralfundraiser/>): This blog post not only covers how to tell a good story, but also essential elements related to using social media.

Using Social Media Effectively

Start with the Official Channel Help Centers:

[Facebook Help Center](#)

[Twitter Help Center](#)

[YouTube Help Center](#)

[Instagram Help Center](#)

"Communication and Social Media: Building an online voice and working smart in a digital world" presented by Denis Costello and Rob Camp from EURORDIS - Rare Diseases Europe (<http://www.patientsacademy.eu/index.php/en/news/480-your-brand-communication-and-social-media>): Access a detailed summary of this expert plenary session from EUPATI (European Patients' Academy on Therapeutic Innovation). A downloadable copy of the presenters' powerpoint slides are also available for learning (<http://download.eurordis.org.s3.amazonaws.com/training-resources/2015/d5s6.pdf>).

"Digital skills boost the power of community" (<https://socialcare.blog.gov.uk/2015/09/16/digital-skills-boost-the-power-of-community/>) by Sarah Purssell: A peer to peer learning scheme from the UK Department of Health encourages us to become digital friends, to ensure more people have access to the health benefits of social media and the internet.

"Five Ways to Ensure Your Site Is Accessible to the Visually Impaired" by Kelli Shaver on Mashable (<http://mashable.com/2011/04/20/design-for-visually-impaired/#z749A4ly4Pq6>): This short article will get you thinking about how to make improvements to your online sites but it's just a start. Take the time to speak to people in your community who live with visual impairments to find out what more you can do.

GCFLearnFree.org (<http://www.gcflearnfree.org/>) offers free online learning opportunities on a range of topics. The technology section (<http://www.gcflearnfree.org/technology>) includes introductory tutorials on social media topics.

RESOURCE GUIDE



“Jab, Jab, Jab, Right Hook: How to Tell Your Story in a Noisy Social World”

by Gary Vaynerchuk

(http://www.amazon.com/gp/product/006227306X/ref=as_li_tl?ie=UTF8&camp=1789&creative=390957&creativeASIN=006227306X&linkCode=as2&tag=vonwongphot-20&linkId=MWDWRGFI4X5TQGYL): New York Times bestselling author and social media expert Gary Vaynerchuk shares hard-won advice on how to connect with customers and beat the competition. This is a blueprint to social media marketing strategies that really works.

“Let’s Get Started! with Social Media” presented by Melissa Hogan during the “Conversations with the Experts” at the 2013 Global Genes RARE Patient Advocacy Summit. The full conference presentation is available here: <https://vimeo.com/75931727>

Marie Ennis-O’Connor, Healthcare Social Media Consultant, shares insights at the **“Health Care Social Media” blog** (<http://hcsmonitor.com/beyond-the-buzz/>) and on LinkedIn (<https://www.linkedin.com/today/author/35897939>). A number of excellent resources by the author have been highlighted throughout the toolkit.

“Maximising Social Media around Rare Disease Day” webinar hosted by Robert Pleticha, RareConnect Project Manager at EURORDIS (<http://www.rarediseaseday.org/page/news/maximising-social-media-around-rare-disease-day>): Special presentation covers tips of how to use Facebook and Twitter to activate your community and build excitement for your Rare Disease Day event.

Mayo Clinic Social Media Health Network (<http://network.socialmedia.mayoclinic.org/>): The Network believes individuals have the right and responsibility to advocate for their own health, and the Network provides useful social media tools to get the best information, and connect with providers as well as one another.

Mayo Social Media Summit – Patient Panel Talk given by Kari Ulrich (<https://www.youtube.com/watch?v=CkOjws71TzE>): Kari Ulrich, a patient with Fibromuscular Dysplasia (FMD), brings perspective to the impact of social media on rare diseases by outlining her experiences and practice recommendations.

Pew Research Center (<http://www.pewresearch.org/>): Pew Research Center is a nonpartisan fact tank that informs the public about the issues, attitudes and trends shaping America and the world. Review the Internet, Science & Tech division for an indepth look at critical trends in these areas. The Health Fact Sheet (<http://www.pewinternet.org/fact-sheets/health-fact-sheet/>) highlights the Pew Internet Project’s research related specifically to health and healthcare.

RESOURCE GUIDE



“RARE Webinar: World Rare Disease Day 2016 Planning” presented by Global Genes (<https://globalgenes.org/wrddplanning2016/>): This hour long session includes many great ideas for using social media to get involved in Rare Disease Day and promote your story.

“Six Steps To A Simple Social Media Strategy” slides by Marie Ennis-O’Connor, Healthcare Social Media Consultant (<https://www.linkedin.com/grp/post/4048287-6014822650013114369>): Straightforward advice for making your own social media strategy.

“#SocialAtMayo - Mayo Clinic’s Social Media Guidelines” (<https://www.youtube.com/watch?v=pjocDhlicJs>): This staff training video provides tips for Mayo’s employees on using social media professionally. While geared at healthcare providers, many parts of the discussion are informative to other healthcare stakeholders.

“Socialize Your Patient Engagement Strategy: How Social Media and Mobile Apps Can Boost Health Outcomes” by Letizia Affinito and John Mack: While this is specially a guide written for pharmaceutical companies, the emphasis on patients as an essential part of the health conversation, makes this is a relevant read to any stakeholders committed to true patient engagement, especially using social media channels.

Social Media Examiner (<http://www.socialmediaexaminer.com/>): A large online social media magazine, Social Media Examiner helps visitors discover how to best use social media, blogs and podcasts to connect with customers, drive traffic, generate awareness and increase sales.

“The Ultimate Guide to Using Images in Social Media” by Saijo George (<http://www.jeffbullas.com/2014/06/23/the-ultimate-guide-to-using-images-in-social-media/>): Useful tips, tools, and resources for making the most of your visuals on social media.

“Utilizing Twitter to Be An Effective #RareDisease Advocate in 15 Minutes A Day” <https://drive.google.com/file/d/0B2Ca00TjC3CpMGpYeThZeHRiaVE/view?usp=sharing>: A PowerPoint presentation prepared by Stephanie D. Fischer, as Former Senior Director of Communications at PhRMA, for the 2014 Global Genes RARE Patient Advocacy Summit.

“Why Content Goes Viral: What Analyzing 100 Million Articles Taught Us” by Noah Kagan at Okdork (<http://okdork.com/2014/04/21/why-content-goes-viral-what-analyzing-100-millions-articles-taught-us/>): An easy to understand article about how to ensure your social media content is as shareable as possible, backed up with data from BuzzSumo (<http://buzzsumo.com/>).

Content Proudly Provided By

Emma Rooney

*Rare Disease Patient Advocate and Storyteller,
My Normal: storytelling for rare disease health,
National Gaucher Foundation of Canada*
<http://globalgenes.org/author/emmarooney>
<http://www.mynormal.ca>
@blumencasey

Global Genes Would Like to Thank All of This Toolkit's Contributors

Kevin Alexander

Filmmaker and Producer of PKULife.tv
<http://www.pkulife.tv>

Marie Ennis-O'Connor

Healthcare Social Media Consultant
https://about.me/marie_ennis_oconnor
@JBBC

Stephanie D. Fischer

*Senior Director, Patient Engagement and
Communications at EveryLife Foundation
for Rare Diseases*
<http://everylifefoundation.org>
@RarePOV

Cynthia J. Frank

*Gaucher Patient and Rare Disease
Patient Advocate*

Melissa Hogan

*Founder and President of Saving Case
& Friends*
<http://www.savingcase.com>
@melissajhogan

Ilana Jacqueline

*Managing Editor of the Rare Daily,
Global Genes*
<http://globalgenes.org/raredaily>
@IlanaJacqueline

Isabel Jordan

*Chair of Rare Disease Foundation
and Patient Advocate*
www.rarediseasefoundation.org
<http://modelingchange.blogspot.ca>
@seastarbatita

Emily Ladau

*Disability Rights Advocate and Owner
of Social Justice Media Services*
<http://wordsiwheelby.com/social-justice-media-services/>
@emily_ladau

Yonatan Maisel

Rare Disease Patient, Advocate and Activist
@Primary_Immune1

Sarah Pecota

Parent of Child with Coffin-Siris Syndrome

Corrie Painter

*Angiosarcoma Survivor and Vice President
of Angiosarcoma Awareness, Inc.*
www.cureasc.org
<http://jamforfries.blogspot.com>
@corrie_painter

Whitney Steele

Parent of a Child with Joubert Syndrome

Bill Strong

Founder of Gwendolyn Strong Foundation
<http://thegsf.org>
@gsfoundation

Benjamin Von Wong

*Photographer & Visual Engineer,
maker of #SavingEliza viral video*
<http://vonwong.com>
@thevonwong
<http://www.curesff.org>
@SavingEliza



My Normal
The National Gaucher
Foundation of Canada
Global Genes

<http://globalgenes.org/toolkits>