



NORD®
National Organization
for Rare Disorders

LEVERAGING SOCIAL MEDIA TO CONNECT WITH THE RARE COMMUNITY



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SOCIAL MEDIA ENGAGEMENT AND YOUR NONPROFIT

Lauren Smith
Communications and Development Manager,
Appendix Cancer PMP Research Foundation



The ACPAMP was created in 2008 by a community of individuals affected by this rare disease. The ACPMP Research Foundation's mission is:

1. *To fund promising, critical research to find a cure for Appendix Cancer, Pseudomyxoma Peritonei (PMP) and related Peritoneal Surface Malignancies (PSM)*

- Only organization completely dedicated to funding research for appendix cancer/PMP
- Has awarded \$1.3 million in the form of 27 research grants, with another \$100,000 to be issued in 2021

2. *To fund educational programs for physicians and patients about these diseases*

- Host in-person and virtual symposiums with leading treatment centers as well as educational webinars with researchers
- Sponsor scholarships for physicians and medical professionals



YOUR AUDIENCE WILL LOOK DIFFERENT ON EACH PLATFORM

- Facebook—fundraisers and news
 - Facebook events, fundraisers and support groups
 - Linking to your website any chance you can
- Instagram—photos and stories
 - Use personal photos of patients and eye-catching graphics with less text
- Twitter—research updates and grant news
 - For us, our Twitter followers are more physicians & medical professionals
 - Cater content to specific channel audience
- Catch people's attention through graphics
 - Canva is easy and free to nonprofits!



A CONSISTENT, CLEAR PRESENCE

- Consistently push content out on any channels that make sense for your organization
- More than just scheduling posts, social media engagement is dynamic
- Post content that represents your brand Keep wording clear and concise
- Remind your supporters of your other channels
- Post FREQUENTLY
 - Stay in people's brains
 - Post at least 2-3 times a week and reiterate important topics with multiple posts
 - Create a “social media calendar” and quick, easy topics that you can post about when nothing else is happening



SOCIAL MEDIA IS NOT A ONE-WAY CHANNEL, NEED TO ENGAGE

Spread your reach—engage!

- Tag relevant accounts, use hashtags, comment back, like comments, etc.
- Social media is not static; it is constant and should feel like an ongoing conversation
- Constantly search social media channels for your disease and relevant terminology
 - Engage whenever your disease comes up on social media
- Reach out to those people through the platform —> work with them and develop partnerships. EX:
 - Doctors now routinely tag us because we've had Twitter engagements organically



KEY TAKEAWAYS

1. Social media should be an engagement and not a one-way communication
2. Tailor social media content for each channel-specific audience
 - Giveaways make for great cross promotions for your platforms. Use your bigger platforms to introduce your current followers to your other social platforms
3. Catch people's attention through graphics and media
 - Canva
 - Personal stories
 - Simple and clear
 - Short videos (1-3 minutes) drive engagement
 - Animoto



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THE MORE WE GET TOGETHER

Tovah Burstein
Community Engagement Director,
FD/MAS Alliance



FD/MAS

ALLIANCE

FD/MAS is a rare, non-inherited, mosaic gene mutation that affects the bones and endocrine system. It can affect just one bone or any number of the 216 bones of the body as well as some or all hormone function.

There is no FDA-approved treatment and many providers are unfamiliar with or misinformed on best practices for managing the disease.

FD/MAS Alliance is a community-led 501c(3) that serves people affected by FD/MAS through programs of research, education and advocacy.

Vounteer Board, Medical and Scientific Advisors, and 1.5 staff people



FD/MAS REGISTRY

- Launched in October 2016
- 15 surveys
- 931 participants
- 180 have completed all their surveys

GOALS FOR OUR REGISTRY

- Capture community priorities
- Understand the level of care beyond research centers
- Generate research interest
- Support for other studies



CHALLENGE: RESEARCH FEELS ABSTRACT

2018

Registry Data Fueled Real Research in 2018!



Four research teams used registry data to strengthen their grant applications to non-FDF grant sources.



Two groups of researchers proposed using registry data and participant recruiting services to build collaborative clinical research networks.



Registry Data was presented at three different conferences this Fall to researchers, biopharma industry professionals, and patient advocates.



Two studies have quickly and efficiently recruited qualified participants from the Registry!



2 research teams have applied for de-identified participant data to better understand FD/MAS



TWO-YEAR ANNIVERSARY: REGISTRY WEEK



A weeklong initiative to increase engagement and push for retaking and updating surveys.

- Social media blitz
- Created a “Patient Toolkit” incentive
- Marketed the registry to researchers

Increased 100% complete #s.

- One-year mark: 87
- Before Registry Week: 103 (+16)
- After Registry Week: 168 (+65)
- Four-year mark: 180 (+12)



90% OF SUCCESS IS SHOWING UP

Campaign's and Context

2016: Initial Launch

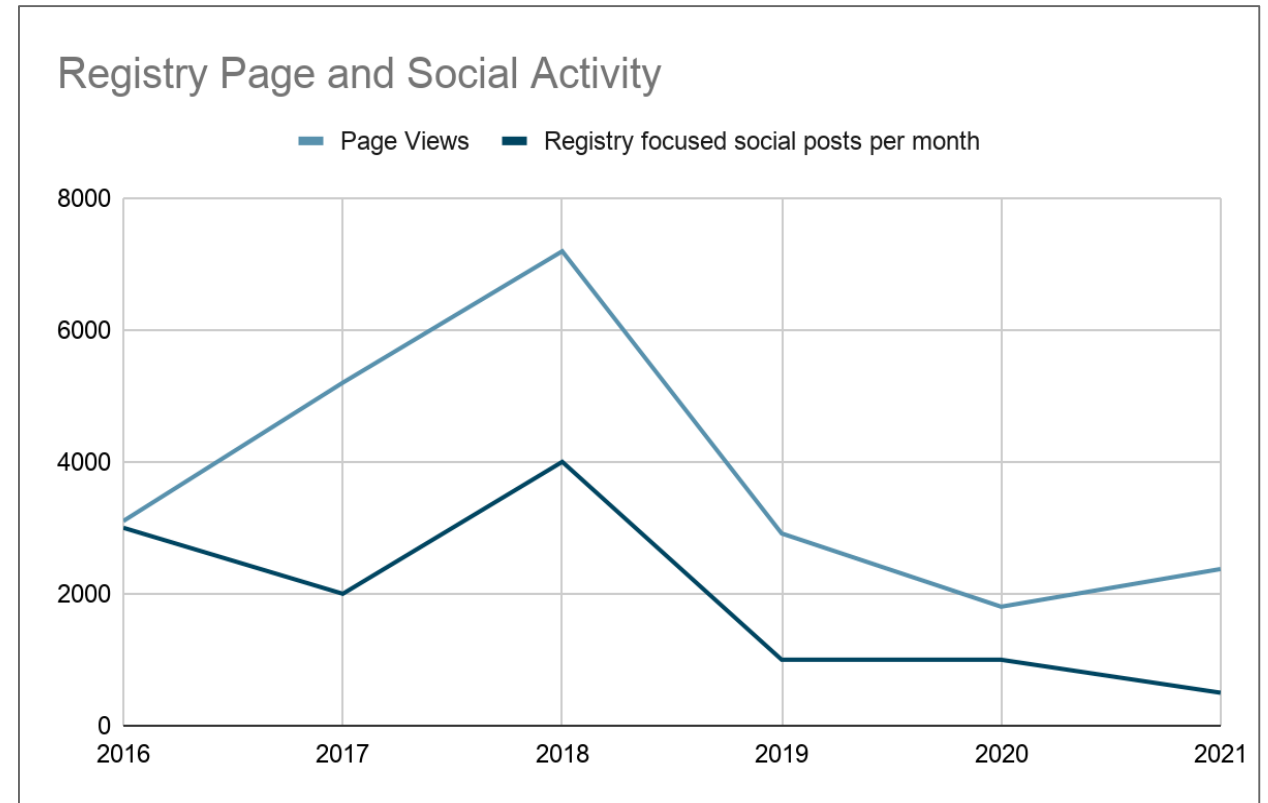
2017: Patient Conference

2018: Registry Week!
Staff hired to manage Registry

2019: Focus on Federal Funding
Staff transitions

2020: Organizational realignment
Thanks to NORD support

2021: Renewed focus





"I find my strength in my daughter's positive attitude. I try to find ways over, under, or around barriers, and **she just breaks right through them.**

Anne C, MAS caregiver,
Lancaster, PA

FD/MAS
ALLIANCE
#FDMASstrength

RENEWED FOCUS: COLLABORATION

Building Relationships

- Brainstorm sessions with patient community
- Solicit feedback from researchers
- Look to the registry community
- Reflect the FD/MAS community (spotlight, tag, reshare)



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LESSONS LEARNED

Joshua Mann, MPH
Director of Health,
VHL Alliance



JOSHUA MANN, MPH DIRECTOR OF HEALTH, VHL ALLIANCE

Who we are:

- 501c(3) nonprofit organization founded in 1993 dedicated to research, education and support to improve awareness, diagnosis, treatment and quality of life for those affected by VHL.

What is VHL?

- Rare inheritable tumor predisposition syndrome causing those who are affected to be at risk for tumors to grow in up to 10 different parts of the body throughout their life

Lessons learned:

- Meet people where they are
- Be the authority
- Protect privacy
- Be clear and concise
- Maintain an active social media presence



LESSONS LEARNED



Meet people where they are.

- When working with people, in order to be effective and efficient in meeting goals, it is important to meet people where they are, both physically and emotionally.
- Trying to oppose people's established preferences is like pushing a boulder uphill.
- Avoid confusion and wasted efforts by utilizing forums and platforms where your community is already accustomed to engaging with you.



LESSONS LEARNED

Be the authority.

- People have questions and they want answers. If you don't provide them, someone else will.
- It is extremely important to quickly correct misinformation in an empathic, but firm, way.
- It is important to control the conversation because misinformation can spread like wildfire. Once it spreads, it can be difficult to correct.



LESSONS LEARNED



Protect privacy.

- People with rare diseases are often hesitant to publicly/openly share about their condition for many different reasons, including perceived social stigma or discrimination (employment, resources, opportunities, etc.).
- By creating a private forum for the community, separate from any public-facing resources, people will feel more empowered and open to sharing personal information and asking for help, without worrying about “outsiders” having too much information about them.



LESSONS LEARNED

Be clear and concise.

- Very often, when people are seeking us out, it is because of a difficult situation that they, or a loved one, are experiencing.
- During these traumatic and overwhelming periods of time, it can be difficult to fully process new information, especially if it is complex and related to the circumstances.
- By keeping messaging clear and concise, it can be more effective and less likely to get lost in the fog.



LESSONS LEARNED

Maintain an active social media presence.

- Most of the work that happens at nonprofits takes place behind the scenes. This has been particularly true during the pandemic.
- It is important to maintain an active social media presence to reassure the community that the organization is operating as business as usual (or as close to it as possible).
- If people feel unconnected and uninformed, they may lose faith that work continues to happen and progress continues to be made, which may end up impacting fundraising efforts.



QUESTIONS - MODERATOR



- What role does social media play in your overall strategic communications strategy?
- What changes to your social strategy has your organization made because of the pandemic that have or will become permanent.
- How has your community adjusted to evolution of social media from being a place to promote events, to the platform where the events are actually hosted?
- What platforms have been key for your communications with your community?
Do you see that changing in the near or long term?
- How do you deal with privacy concerns? Trolls? What role does moderation and codes of conduct play for your work?
- Is your focus primarily on recruiting, informing or driving contributions?
If all of the above, how do you balance it all?



QUESTIONS & CONTACT INFORMATION

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Thank you.

