RareLaunch: Getting the Word Out: Growing Your Nonprofit

Nathan Peck, Cure VCP Disease Inc.
Becky Strong and Patrick Dunn, International Pemphigus & Pemphigoid Foundation
FORMING A FOUNDATION WORKSHOP

Cure VCP Disease
Nathan Peck, CEO
December 2, 2020
• Valosin Containing Protein (p97 gene)
  o Mutant VCP does not degrade proteins properly allowing various central nervous system, peripheral nervous system and skeletal system diseases to take place
  o Also called multisystem proteinopathy & IBMPFD
• Adult onset & autosomal dominant
  o Affects families
  o Unknown how many affected (<2,000)
• Many patients misdiagnosed with LGMD, sIBM, MS
• Multiple, disparate phenotypes (even among family members)
My Patient Advocacy Perspective

- Founded as a 501(c)(3) in February 2018
- Only patient advocacy organization for VCP disease & IBMPFD
- Entirely volunteer-led
- Three-person Medical Advisory Board
- Seven-member Board of Directors (initially met twice monthly, now monthly)
- Primary mission to drive disease awareness, identify patients & drive therapeutic development

Milestones

- **Cure VCP Disease Patient Registry**
  - Live June 2018

- **First ever Patient & Caregiver Conference**
  - April 2019

- **FDA Patient Listening Session**
  - May 2020

- **First North American VCP Scientific Focus Group**
  - June 2020

- **Phase 1 Remote Functional Measure Study**
  - October 2020
Build Credibility, It Takes Time!

2018
- First Patient Call
- Reach 30 patients in registry
- Second patient call
- Rare Disease Week on Capitol Hill

2019
- First patient conference
- Rare Disease Orphan Drug Congress
- MDA Scientific & Clinical Conf
- Join NORD
- Reach 200 patients in registry
- Global Genes Advocacy Summit
- Awarded Global Genes Support Grant
- Fourth patient call

2020
- Publication on Cure VCP Disease Registry
- Connect with media and rare disease researchers
- 3rd rare patient Happy Hour
- Completion: Phase 1 successfully funded and research continues
Understand the disease and researcher landscape

1. Use NIH Project RePORTER to identify researchers and projects
   • Contact the researchers and introduce your organization
2. Scour PubMed (setup weekly notifications), Google Scholar, ResearchGate, etc. for publications
   • First author – did most of the work
   • Last author – Lab and/or senior advisor
   • Everyone else – collaborators
3. Exhibit at conferences

Provide opportunities for researchers and patients

1. Create a social media presence and branding
2. Speaking engagements
   • Patient webinars
   • Patient & caregiver conferences
3. Organize a scientific conference or scientific focus group
4. Provide data to assist with publishing
5. Most importantly, build trust, let researchers know that you are here to help them succeed.
Educatng Parents, Families and the Public

Be Scrappy
High Powered and Low Cost

Our Research Tools
- AllStripes
- CoRDS Registry

Our Collaborative Relationships
- NORD
- Global Genes
- RDLA
- AFTD
- researchmatch.org
- TREAT-NMD
- MDA
- MyGene2
- Patients Alliance
- indiaware

Our Online Tools
- Wix
- Mailchimp
- Zoom
- Canva

Financial / Fundraising
- Network for Good
- Wave
- Nonprofits Insurance Alliance Group
- Charity Compliance Solutions
- NOLO

Social Media
- Hootsuite
- YouTube
- LinkedIn

rarediseases.org
Thank you!

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Let’s talk: https://bit.ly/talkvcp
RareLaunch: Getting the Word Out on Social Media

Becky Strong and Patrick Dunn,
International Pemphigus & Pemphigoid Foundation
WHO WE ARE: PROGRAMS

Becky Strong
Outreach Director

Patrick Dunn
Marketing and Communications Director

pemphigus.org
WHO WE ARE

- Established in 1994
- Mission: to improve the quality of life for all of those affected by pemphigus and pemphigoid through early diagnosis and support
- Programming includes Peer Health Coaches, Patient Education Webinars, Regional Support Groups and Find a Doctor Map, Awareness, Research, Advocacy
PEER HEALTH COACH PROGRAM

• Patients with pemphigus and pemphigoid
• Are not medical professionals
• Information shared is for educational purposes only
• Coaches share tips, tricks and medically-reviewed information from their own journey
PATIENT EDUCATION WEBINARS

- Live webinar with experts
- Q&A session
- Wide range of topics
- Last approximately one hour
SUPPORT GROUPS

- Regional support groups
- Virtual support groups
- Online chat platforms
FIND A DOCTOR MAP

Currently taking new patients, as well as which insurance providers are accepted. The IPPF does not maintain this specific information.
AWARENESS PROGRAM

Outreach is directed to dental professionals through student and continuing education, who have the unique opportunity to shorten diagnosis times.
RESEARCH AND ADVOCACY
SOCIAL MEDIA
SOCIAL MEDIA

• Demographics: Where is your community already online?
• Focus on engagement: one-two channels vs spreading your efforts too thin
• However, claim all accounts now (hopefully with the same username)
• Personal vs organization accounts
• Who should manage?
“WHAT GOOD CAN WE DO WITH SOCIAL MEDIA?”

Social media is NOT . . .

• Your organization’s website
• HIPAA compliant (I am not a compliance expert)
• Friendly to your database/CRM
“WHAT GOOD CAN WE DO WITH SOCIAL MEDIA?”

Social media allows us to reinforce our missions, visions, messages, and programs by meeting people where they are.

It allows our organizations to participate in conversations that are already happening and start new ones that need to happen.
ENGAGE AND GROW: CONTENT

Aim to provide useful content and information more often than promotional posts

- Patient stories (with consent)
- Use images/graphics/video
- Share posts from other organizations that would be helpful to your community
- Information about your programs when it’s useful to your audience (events, webinars, links to downloadable resources on your website, etc.)
If you’re regularly providing useful content, your “asks” are more likely to be answered

- Fundraising
- Event promotion
- Advocacy calls to action
RESOURCES

**Graphics/Design**
- Canva
- Unsplash
- Pexels
- Pixabay

**Social Media Management**
- Loomly
- Hootsuite
- Buffer
- Excel/Google Sheets/Airtable

**Social Media and Nonprofit Marketing Info**
- Julia Campbell: https://jcsocialmarketing.com/
- Nonprofit Marketing Guide: https://www.nonprofitmarketingguide.com/
- Classy.org Blog: https://www.classy.org/blog/
Thank you!