



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

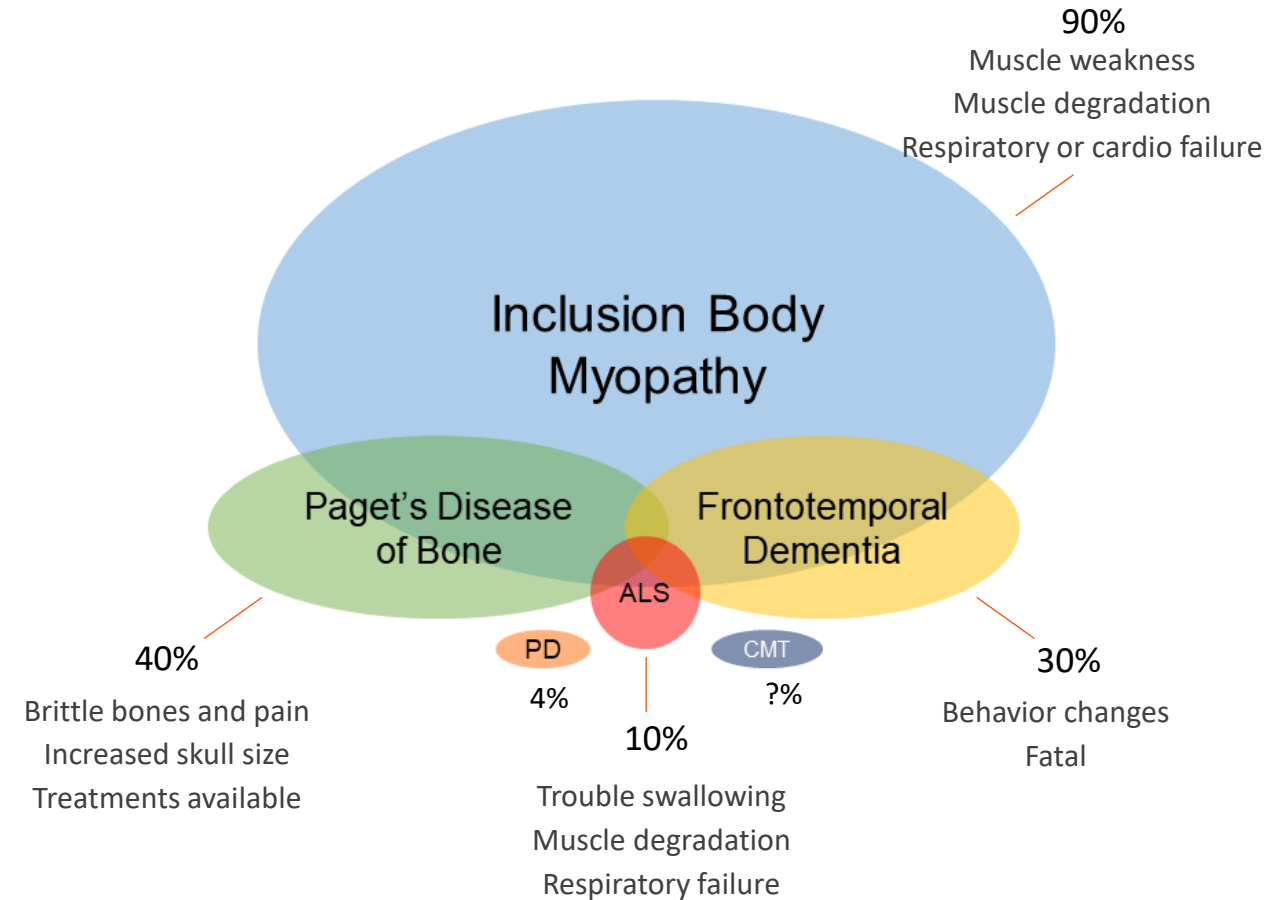
Nathan Peck, CEO

December 2, 2020





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



Al-Obeidi, Clin Genet, 2018

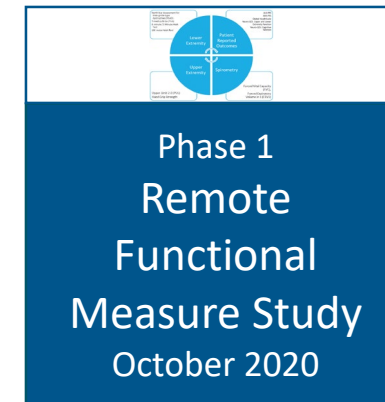
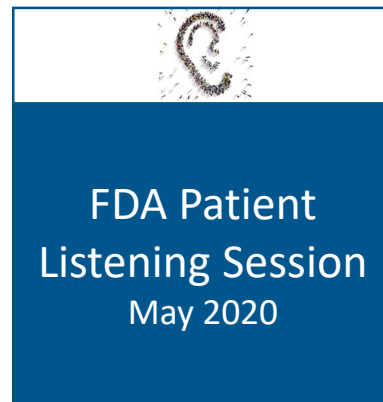
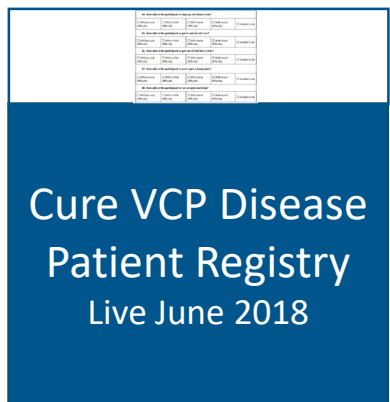


My Patient Advocacy Perspective

- 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

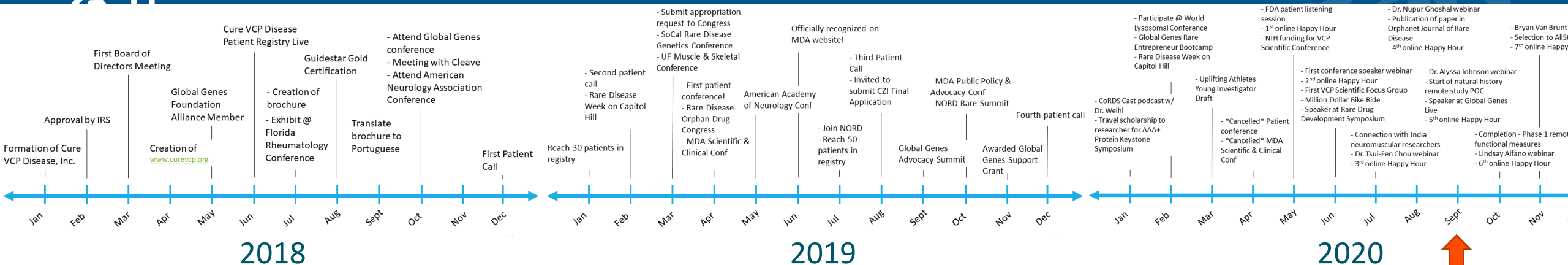


Milestones





Build Credibility, It Takes Time!



- ☒ Patient registry?
- ☐ Natural history study?
- ☐ Mouse / iPSC models?
- ☐ Biomarkers and endpoints?
- ☒ Do researchers and scientific leaders know you?



Publication on Cure VCP Disease Registry



Network, Network, Network

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

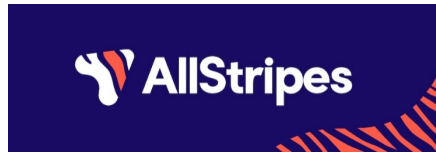
1. Create a social media presence and branding
2. Speaking engagements
 - Patient webinars
 - Patient & caregiver conferences
3. Organize a scientific conference or scientific focus group
4. Provide data to assist with publishing
5. Most importantly, build trust, let researchers know that you are here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





Be Scrappy High Powered and Low Cost

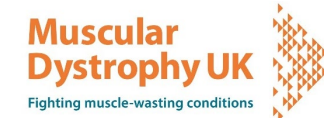
Our Research Tools



Financial / Fundraising



Our Collaborative Relationships



Our Online Tools



Social Media



rarediseases.org



Thank you!



Nathan Peck

CEO, Cure VCP Disease

Website: <https://www.curevcp.org>

E-mail: nathan@curevcp.org

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




What are Pemphigus and Pemphigoid ▾ Patients ▾ Healthcare Professionals ▾ About Us ▾ Get Involved ▾ News & Events ▾ [Donate](#) 


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


United States ▾

Enter Zip Code ... 



Los Angeles 

Map Satellite





Map data ©2020 Terms of Use Report a map error





AWARENESS PROGRAM

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

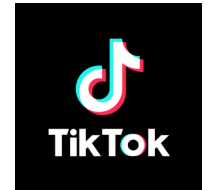


RESEARCH AND ADVOCACY





SOCIAL MEDIA



RareConnect.org



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.)



ENGAGE AND GROW: PROMOTE



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!

