

Leveraging Social Media To Engage Patients in Research

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Roundtable on Social Media
& Patient Engagement
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Our beginnings...



- ❑ conceived in a hospital bed
(not as exciting as it sounds...)
- ❑ born on a blog (POTSgrrl)
- ❑ raised on Facebook
- ❑ now on Twitter, Vimeo, YouTube, Pinterest & Vine

What do we use social media for?



Empowering patients through...

- ❑ education
- ❑ support/encouragement
- ❑ help finding doctors
- ❑ in person meet-ups/events
- ❑ webinars/live Q&A
- ❑ content to educate others

What do we use social media for?



Other uses...

- ❑ caregiver support
- ❑ #MedEd
- ❑ public awareness
- ❑ fundraising
- ❑ research recruiting
- ❑ expanding our network

Engaging patients in research...



- ❑ study design ideas
- ❑ identifying needs
- ❑ editing study protocols/surveys
- ❑ beta testing surveys
- ❑ fundraising
- ❑ research recruiting
- ❑ disseminating research findings

Funding Medical Research

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT



Vanderbilt's "Road Trip Research Lab"
at the 2014 Dysautonomia International Conference

Funding Medical Research

DYSAUTONOMIA INTERNATIONAL



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Spreading the word...

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

Chicago Sun Times

Cosmopolitan

CrowdMed

The Huffington Post

Mayo Clinic

Neurology Now

Newsday

New York Post

The New York Times

US News & World Report

...and dozens of local media outlets



COSMOPOLITAN

Newsday

NEW YORK POST

**The
New York
Times**

Research Recruiting Through Social Media



- Recruiting for lab based studies
- Recruiting for online survey studies
- Enrolling patients in study databases
 - ResearchMatch
 - Autonomic Disorders Consortium

Global Interactive Dysautonomia Map



Research Recruiting Through Social Media



- ❑ Brain Fog in POTS
 - 138 patients
 - journal article published Sept. 2013
- ❑ Physician Patient Interaction in POTS
 - 700 patients
 - identified avg. diagnostic delay of 6 years
 - self-published, lead to HuffPost articles
- ❑ Hydration Preferences Survey
 - 1000 patients in one week
 - still analyzing data

Research Recruiting Through Social Media



Coming soon... *The Big POTS Survey*

Dysautonomia International &
Vanderbilt University collaboration

*Diagnosis and Impact of Postural Tachycardia
Syndrome – An International Survey*

Will recruit 1000+ patients in the 1st month.

Will be the largest POTS study to date.

Made possible by our social media reach.

Our Social Media Reach



- 10,500 Facebook followers (main page)
- 50,000+ FB post impressions per week
- 11,000 private group members on “POTS”
- 2,500 Twitter followers (many MDs/RNs)
- 17,000 unique web visitors per month

Join the conversation!



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