

# AMERICA DISABLED?: AN INTERNSHIP WITH DYSAUTONOMIA INTERNATIONAL

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DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT



## WHAT IS DYSAUTONOMIA?

According to Dysautonomia International (DI)"  
[d]ysautonomia is an umbrella term used to describe several different medical conditions that cause a malfunction of the Autonomic Nervous System. People living with various forms of dysautonomia have trouble regulating bodily systems. As a result of their condition, one can experience lightheadedness, fainting, unstable blood pressure, abnormal heart rates, malnutrition, and in severe cases, death.

Dysautonomia is not rare. Over 70 million people worldwide live with various forms of dysautonomia. People of any age, gender or race can be impacted. There is no cure for any form of dysautonomia at this time..."\*



AWARENESS

### Readings & Weekly Discussions

- Prioritized scholarship and theories from disabled authors
- Troubling of disability the categorization and overlap of terms and labels such as: [chronic] illness and disability

### Internship Site

- Moderated Facebook community groups (state, identity group, region, and age)
- Hosted and moderated over twenty Zoom Meetups for individuals and caregivers impacted by DI (including leadership of College Support Group)

## WHO IS DYSAUTONOMIA INTERNATIONAL?

- 501(c)(3) non-profit, founded in 2012
- Large network of volunteers- patients, family members, friends, physicians, researchers, and other health professionals
- Annual Conference
- Support Groups
- October is Dysautonomia Awareness Month
- Funding for medical research
- Sharing of knowledge, resources, community, and personal experience of living with various forms of Dysautonomia



ADVOCACY

### Readings & Weekly Discussions

- Examined the complexities and questions around the idea and language of "cure" in relation to disability
- Identity politics
- Role of social movements/civil society
- Individual experiences and decisions around active or non-active participation and/or mobilization
- ADA's framework and limitations in its ability to address individual and collective challenges to equality and inclusion

### Internship Site

- Building community and sharing experiences to further DI awareness

## LEARNING GOALS

- Engage with disability nonprofit principles, objectives, and obstacles.
- Reflect on the formal arrangements that shape communities in a people-first environment
- Evaluate and apply disability resources (in terms of audience, purpose, and goals) within the larger social justice network and understandings of inclusivity



ADVANCEMENT

### Readings & Weekly Discussions

- Problematized the role of self via different models of disability and one's intersectionalities
- Engaged with themes of inclusivity, and reflected on funding structures for research and DI itself.

### Internship Site

- Created spreadsheets with medical provider resources from peers within the Dysautonomia Facebook Group
- Hosted and moderated a webinar with HIPPA specialist for Dysautonomia Community Members

### Personal Connection & Reflection

I am a person with POTS.  
I am a person *with* a disability.  
Working with Dysautonomia International has allowed be to become a stronger advocate, listener, and gain a sense of identity within the disability community.

### Takeaways from Praxis

- Broader understanding of community and people-first based nonprofit
- Explored the limitations and boundaries of a community fighting for a "cure" and identity on disability
- Questioned and reflected what it means to fight for "social justice" and "equality" and actors involved

### Suggested Authors from Syllabus

Lennard Davis. (2013). The Disability Studies Reader (4th edition)  
Wong, Alice. (2020). Disability/Visibility.  
Works by Haben Girma

Learn more about Dysautonomia International

