



Accessing Local Resources

Sandi Brettler MSN, RN, CNRN – Clinical Nurse Specialist
Penn State Health, Hershey Medical Center
Hershey PA



March 27-29, 2025
Planet Hollywood
Las Vegas, NV

DISCLAIMER



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PRESENTER DISCLOSURES

I have no commercial or financial relationships to disclose.

I am currently a board member for the National Ataxia Foundation.

I am currently working for Penn State Health Hershey Medical Center.



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- Accessing daily living resources can significantly improve quality of life for people living with ataxia. This session will discuss some useful resources for daily living that might be helpful, including support organizations at the national, state and local level for issues concerning assistive devices, transportation, financial, educational and family/caregiver needs.



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National Groups



- National Ataxia Foundation
- Other Movement Disorder or Ataxia Groups
 - Parkinson's Foundation, FARA, Essential Tremors
- NORD
- Lions Club International, Kiwanis, Rotary Clubs
- Ataxia Centers of Excellence
- National Association of Elder Law Attorneys
- American Association of Adapted Sports Programs
- Global Genes
- United Way



NORD[®]
National Organization
for Rare Disorders

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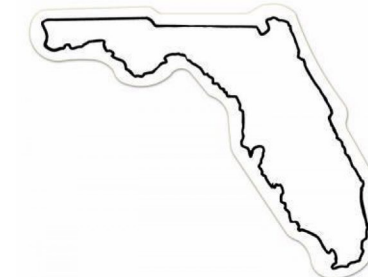
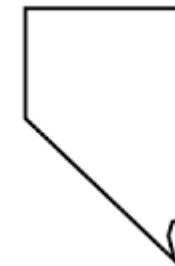


Global Genes[®]
Allies in Rare Disease



Statewide Assistance

- Medicare/Medicaid, SSDI/SSI
 - Waiver programs to help with home care
- Partners in Policy Making
- Independent Living Centers
- Office of Vocational Rehabilitation
 - Can also assist with college tuition, books
 - PA provides for up to the equivalent of a community college tuition per semester
- General resources
 - Nevada 211 – app or www.nevada211.org
 - Transportation assistance programs
 - Illinois DHS – AABD Cash



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Transportation/Mobility assistance

- Moving Forward 4 Ataxia
- Veterans of Foreign Wars, American Legion
- Local churches, flea markets, estate sales, thrift shops, Facebook Marketplace or Free groups
- Stellantis DriveAbility Grants and Funding
 - www.stellantisdriveability.com/grants-and-funding
- Mobility Works
 - www.mobilityworks.com/financing/automotive-mobility-programs/
 - They can work with your local car dealerships



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Air Transportation/Mobility assistance



- TSA Cares
 - TSA notification card
 - <https://www.tsa.gov/travel/tsa-cares> or call TSA Cares (855) 787-2227
- DPNA or SSR codes can be requested when booking flights
 - Request directly through airline, on-line booking or through travel agent
 - JetBlue, Southwest, United, Virgin Atlantic, Alaska Airlines, American
- No consistent regulations for air travel internationally
 - Check with individual airport authorities or country/region where you are traveling – some are VERY unclear
 - Early notification is essential



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Ability Awareness Meet Ups

- Philly Bike Expo – Philadelphia, PA 2026 dates TBD
- Moments of Joy Fest – Houston, TX 2025 dates TBD
- Penn State Health Rec Fest – Lancaster, PA 8-23-25
- Abilities Expo – Long Beach, CA 3-27-26
- Disability Expo 2025 – Jacksonville, FL 7-26-25
- New York Metro 2025 – New Jersey Convention Center 5-2-25
- Disabilities Expo 2025 – Ft. Wayne, IN 5-10-25



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Local Backyard Resources

- High school Key Clubs
- Boy Scout/Girl Scout organizations
- Church/Temple youth groups
- NAF support groups
- Therapeutic horseback riding clubs
- Local gyms/YMCA/YWCA
 - Rock Steady Boxing Program, Adapted Sports programs
- Hospice/Palliative Care/Home health agencies





The Internet

- Be careful what you interact with!
 - Dr. Google does NOT have a medical degree – stick with the ones that do!
- Start with the NAF home page – best resource out there
- www.ataxiaconnection.org
- www.dayundefined.com
- Ataxia Centers of Excellence





Facebook



- Facebook groups
 - FODAC – Stone Mountain, GA - public
 - Central PA Ataxia Support Group – private group
 - Friedreich’s Ataxia – public group
 - Friedreich’s Ataxia Parents, Family, and Friends Group; Fawesome Mums; Friedreich’s Ataxia Community
 - Bill Nye the Science Guy
 - Living with Ataxia
- ****Be cautious about sites that don’t seem legit****
 - Especially ‘research sites, independent doctors, etc.’ Always question the credibility...



Instagram

- Instagram groups
 - ataxia_and_me
 - the_ataxia_caregiver
 - billnye
 - friedreichsataxianews
 - broadwayforataxia



Bill Nye:
The Ataxia
Advocate Guy



JOIN US AT
Broadway for Ataxia



MARCH 20TH AT 6:30 PM EST

WE WOULD LIKE TO INVITE YOU TO THIS MONTH'S FREE SESSION! THERE WILL BE SINGING, DANCING, AND GREAT EXERCISES FOR EVERYONE!

LINK ON: WWW.BROADWAYFORATAXIA.ORG



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YouTube – Neurointensive Exercise

@MovementRevolution
www.movement-revolution.com

https://www.youtube.com/shorts/5SGO_7IV6cM
[@physiodeft](#)

Little Steps, Big Gains
[@littlestepsbiggains](#)
https://www.youtube.com/channel/UCamLVWEe_fq5FJmDE5ds5nQ

Cerebellar Ataxia Exercises
[@JohnsHopkinsMedicine](#)





Questions?

- Feel free to contact me with any questions!
- Sandi Brettler RN sbrettler@hotmail.com

