

# **Managing Ataxia and Managing Your Neurologist (and Your Primary Care Physician and Your Insurance Co...)**

**Or why they should all attend this conference**

**Susan L. Perlman M.D.  
Clinical Professor of Neurology  
David Geffen School of Medicine at UCLA  
Director, Ataxia Center**

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# On This Day in History

## March 22

All beginnings are difficult--

- 1621 - The Pilgrims of Plymouth Colony sign a peace treaty with Massasoit.
  - 1622 - Jamestown massacre: Algonquian Indians kill 347 English settlers around Jamestown, Virginia, a third of the colony's population.
  - 1630 - Massachusetts Bay Colony outlaws the possession of cards and dice.
- But 1933 - [President](#) Franklin Delano Roosevelt signs into law a bill legalizing the sale of beer and wine.

Some things will always be with us—

- 1765 - The Parliament of Great Britain passes the Stamp Act, which introduced a tax to be levied directly on its American colonies.
- 1963: The Beatles' first album, "Please Please Me," is released in Britain; it is soon number one on the pop charts.
- Birthdays
  - 1887 - Chico Marx, American comedian and actor (d. 1961)
  - 1931 - William Shatner, Canadian actor
- Deaths
  - 1832 - Johann Wolfgang von Goethe, German writer (b. 1749)
- In 1993 the United Nations General Assembly declared March 22 as World Day for Water
- Saints Days--St. Basil of Ancyra
  - St. Nicholas Owen, a Jesuit, used his skills to build secret hiding places for priests throughout England

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# We are all rather like guerrilla warriors

- **Guerrilla warfare** (“little war”) is the unconventional warfare and combat with which a small group of combatants use mobile tactics (ambushes, raids, etc.) to combat a larger and less mobile formal army. The guerrilla army uses ambush (stealth and surprise) and mobility (draw enemy forces to terrain unsuited to them) in attacking vulnerable targets in enemy territory.
- Guerrilla tactics are based on intelligence, ambush, deception, sabotage, and espionage, undermining an authority through long, low-intensity confrontation.
- So we find our way around and through problems, but, our ultimate goal should be to change the health care policy that gets in the way of patient care.

# **So, where is the battle?**

- **Communication with your doctor**
- **What you can reasonably expect from your doctor**
  
- **Communication with your insurance company**
- **What you can reasonably expect from your Ins. Co.**
  
- **Each individual ataxan's battle plan will be different.**

# Communication with your doctor

## What you can reasonably expect from your doctor

- Patients are frustrated at:
- how few physicians are familiar with ataxia,
- how long it takes to be diagnosed,
- the frustration of having no diagnosis or given no cause for their ataxia,

THESE ARE REMEDIABLE THROUGH EDUCATION AND RESEARCH

- how little neurologists have to offer after they give them the diagnosis,
- and then, interestingly, when they do get a diagnosis - the hopelessness of it from the neurologist's viewpoint. Patients ask, "Am I supposed to just lay down and die?" Some doctors have essentially said, "Yes."

THESE ARE LESS EASY TO UNDERSTAND AND FIX—  
BUT, THERE IS ALWAYS SOMETHING THAT CAN BE DONE NOW AND  
IN THE FUTURE.

AND, YOUR COMMON SENSE TELLS YOU WHEN THE WAY YOU'RE  
BEING SPOKEN TO IS JUST WRONG.

# **THE EMPOWERED PATIENT**

From a survey by Elizabeth Cohen of CNN Medical News

- 1. You should be seen in a timely manner when you're sick.**
- 2. You should get results in a timely manner.**
- 3. Your doctor, not the staff, should call you with bad results.**
- 4. Your doctor should tell you what medicines you're getting the their side effects.**
- 5. Your doctor should explain everything in terms you can understand.**
- 6. You should be treated with respect.**

# Diagnosing Ataxia is Not Simple

- Ataxias are rare diseases—doctors may be unfamiliar with them  
Estimates are SCAs 1-5/100,000 population  
FA 2-3/100,000  
Compared with Alzheimer's 1600/100,000  
Parkinson's 180/100,000
- The true nature of an ataxia may not reveal itself for up to a year or two.  
So, the first visit to a doctor may not nail the diagnosis or cause.
- At best only 50% of ataxias are inherited, there are only a few genetic tests available, and some insurances do not pay for them.  
Very few non-genetic causes are known.  
So, of my genetic cases, only half actually receive a genetic diagnosis.  
Of my non-genetic cases, only half receive an explanation of cause.  
This does limit the doctor's ability to recommend treatment or to do accurate genetic counselling. You may not get answers to all your questions.

# What Can You Do to Help?

**Your health is a valuable resource—treat it like any other investment. Do not become one of Bernie's sheep.**

- Treat your doctor as an ally, not an adversary.
- Establish a continuing relationship with your doctor.
- Know when to ask for a second opinion, if your doctor seems stuck.
- Keep organized records of your medical history and tests.
- Bring a written list of questions to each visit. Be specific.
- Be proactive—if you see an article or hear about something that might pertain to your ataxia, bring it in.
- If there are too many questions or articles for one visit, prioritize and save some for next time.
- Less urgent concerns may be able to be handled via email.
- Use your primary care doctor to help sort out symptoms that relate to your ataxia and symptoms that might be from something else.
- If an explanation is not clear, ask for clarification. Do not leave the doctor's office confused. Ask for explanations in writing to take home.

## **Communication with your insurance company**

### **What you can reasonably expect from your Ins. Co.**

- If anyone has an insurance company that has reasonable rates, has an open and transparent policy of coverage, is easy to reach, and responds in a reasonable amount of time, please let me know who these people are.
- Your doctor may find it easier now to justify various tests, including genetic testing, and off-label use of drugs, because of the growing number of scientific publications. He will have to convince the insurance company that you will benefit from these—but, then, he has to convince you of that as well.  
FARA's Off-Label Drug Use guides will soon be available.
- A word about MediCare and Medicaid—big brother is watching, fraud investigations do happen, and we all want to behave ethically, even if it seems that the rules as they exist are not.

# **The Seven Habits of Living with Ataxia (with apologies to Stephen R. Covey)**

- **Why 7? You can count them on one hand.**  
(Those of you so gifted, please see me after the presentation.)
  1. **Information**
  2. **Explanation**
  3. **Evaluation**
  4. **Rehabilitation**
  5. **Relief of Symptoms**
  6. **Access to Research**
  7. **Someone to Pay It Forward To**
- **Finally, Hope and Cope is giving way to  
Advance and Attack**

# **1. Information—it's at our fingertips**

**NAF, FARA, other ataxans, Internet, your doctors**

- WHAT IS ATAXIA?**
- WHAT CAUSES IT?**
- HOW DO GENES CAUSE ATAXIA?**
- CAN ATAXIA BE TREATED/CURED?**
- CAN NERVES BE HEALED/REPLACED?**
- IS THERE ANY RESEARCH BEING DONE?**
- IF I HAVE MORE QUESTIONS, WHO CAN I ASK?**

## **2. Explanation**

**Trusted and knowledgeable health care providers**

- WHAT DO I HAVE?**
- WHAT IS THE CAUSE OF MY ATAXIA?**
- ARE MY CHILDREN AT RISK?**
- CAN IT BE CURED?**
- WILL IT GET WORSE?**
- HOW BAD WILL IT GET? HOW SOON?**
- CAN MY SYMPTOMS BE TREATED?**
- HOW CAN I GET INVOLVED IN RESEARCH?**

# 3. Evaluation

**You, your doctor, and your insurance company**

- **Testing to make sure it really is ataxia (exam, MRI, LP)**
- **Acquired factors--prior illnesses**
  - toxic exposures**
  - medication (Dilantin, amiodorone)**
- **Other medical problems--thyroid dysfunction**
  - low B12 or E**
  - syphilis, EBV, Lyme, HTLV1**
  - rheumatologic, vascular**
- **Immune/paraneoplastic--anti-GAD, anti-gliadin**
  - anti-Yo, Ri, MaTa, CV2, Zic4, others**
- **Genetic causes**

# **4. Rehabilitation**

**Demand it, it helps**

- **Goals--safe mobility (including driving)  
independence in activities of daily living  
intelligible speech or other communication  
safe swallow, stable nutrition  
safe airway  
control of deconditioning, fatigue, and pain**
- **Physical Therapy, Occupational Therapy, Orthotics,  
Speech and Swallowing Therapy, Nutrition,  
Ophthalmology, Home Health Assistance, Genetic  
and Psychosocial Counselling, Legal Aid, Support  
Groups, IEP with schools**

## **5. Relief of Symptoms**

**Never let your doctor say there's nothing he can do**

- **Imbalance, falling**
- **Incoordination of hands, clumsiness, dropping things**
- **Tremors of head, hands, or legs**
- **Slurred or slow speech, altered breathing/sleeping**
- **Difficulty with swallowing, choking, nutrition**
- **Blurred, jumping, or double vision**
- **Dizziness or vertigo**
- **Fatigue, sleep problems, pain, bowel/bladder issues**
- **Possible difficulty with reasoning, language, memory, or personality and behavior**

## **6. Access to Research**

**You and your doctor can both find these resources**

- **The NAF, FARA, and A-T Family network raise the research money and know where it is going.**
- **Ataxia AND Research=1,320,000 hits on Google.**
- **Clinicaltrials.gov with your morning coffee.**
- **Access to research is only a mouse-click away and will get even easier with a National Ataxia Registry.**
  
- **There are now comprehensive ataxia programs (diagnosis, treatment, and research) in 20 states, united under the Cooperative Ataxia Group.**

# **A WORD OF CAUTION**

- **As accessible as many of these ataxia experts are, via mail, phone, and email...**
- **As good as the various ataxia websites are...**
- **As popular as Web MD is...**
- **Electronic medicine will never replace a caring and knowledgeable flesh and blood physician...or caring and knowledgeable friends who have travelled the ataxia road before you.**

## **7. Someone to Pay It Forward To**

- 90% of what I know about ataxia I've learned from my patients.**
- The other 10% I've learned from my colleagues.**
- I am extremely grateful to every one of them.**
- We all need to share questions, concerns, ideas, and information with other ataxans and their families, with our health care providers, and with the public at large.**
- We can win the “little war” and the big one.**

# Partners in Clinical Neurogenetics Research at UCLA

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- Pari Young, M.D. (Huntington's disease)
- Eric Wexler, M.D., Ph.D. (Psychiatry)
  
- La Toya Carter — clinic coordinator (310) 825-3370
- Lynn Kessler, Ph.D., Sharone Trifskin, M.S. — Friedreich's ataxia coordinators (310) 206-8153
- Barbara Fallick, MSW — Social Work Coordinator (310) 794-1225
- Michelle Fox, M.S. — Genetic Counselor (310) 206-6581
- Sakena Patterson — Database Research Assistant
- Jeanette Papp Ph.D. — Database Developer
- New Patient Appointments — (310) 794-1195 and follow the menu

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# THANK YOU

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