

Socio-Economic consequences of Epilepsy

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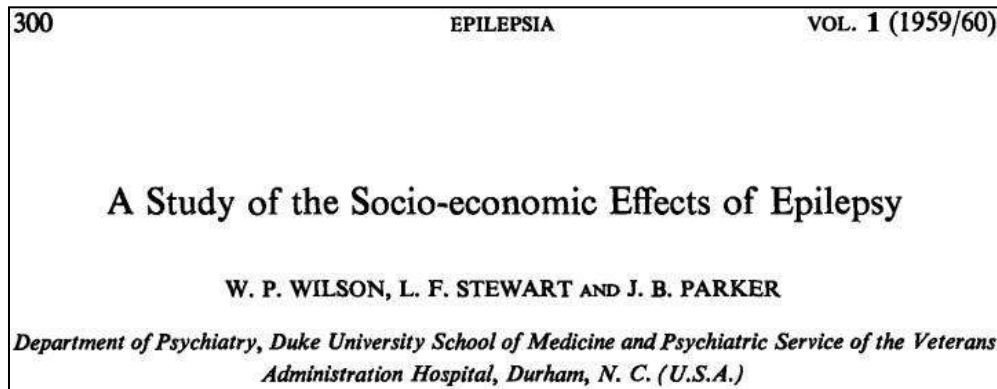
Introduction

- Epilepsy is often a life-long problem
- Seizures are not the only problem, and treatment of seizures is not the only help patients need.
- The social and economic problems caused by epilepsy are often under-appreciated (*by physicians*)
- Physicians often don't address these issues, because we don't have any specific training regarding these problems.

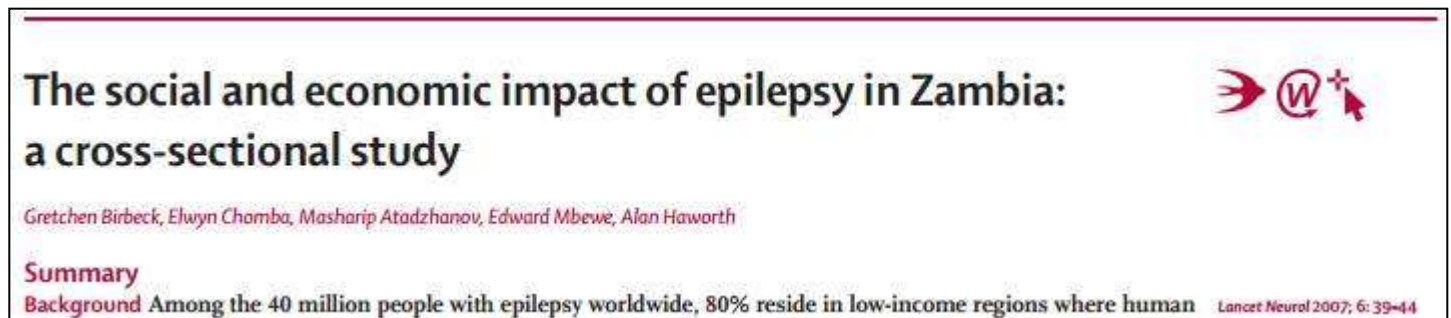
Introduction

Social and economic problems with epilepsy:

1. Have been known to be a problem for a long time



2. Occur throughout the world



Introduction

The most important things for me are:

- To let you know that you are not alone.
- To review the problems that you face (*please tell me!*)
- To review possible solutions
- To reassure you that a full, happy life is possible

1. You are not alone



1. Epilepsy affects **0.5 to 1 %** Percent of the population.
70% of people experience remission during their lifetime
2. How many people have epilepsy in the US?
3. In the World?
4. What proportion of these have social and economic problems?

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3 million!
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2. How many people have epilepsy in the US?
3 million!
3. In the World?
50 million!
4. What proportion of these have social and economic problems?

1. You are not alone

4. **How many people with epilepsy have social and economic problems?**
 - ❖ Not a simple question to answer!
 - ❖ Differs over time, from country to country, and state to state
 - ❖ Probably, all patients.
 - ❖ Lets look at some studies...

1. You are not alone

- 4. **How many people with epilepsy have social and economic problems?**
 - **1/4 of all patients** report that social stigma, fear of other people's reactions, shame, and loneliness are major concerns¹

 - **Germany, Italy, USA – 15 to 20% unemployed**²
 - **PWE had an average income of \$18,750** compared with \$32,000 for the general public. ³

 - **46% (almost half) of PWE reported poor quality of life** compared with 19% without epilepsy⁴

1. You are not alone



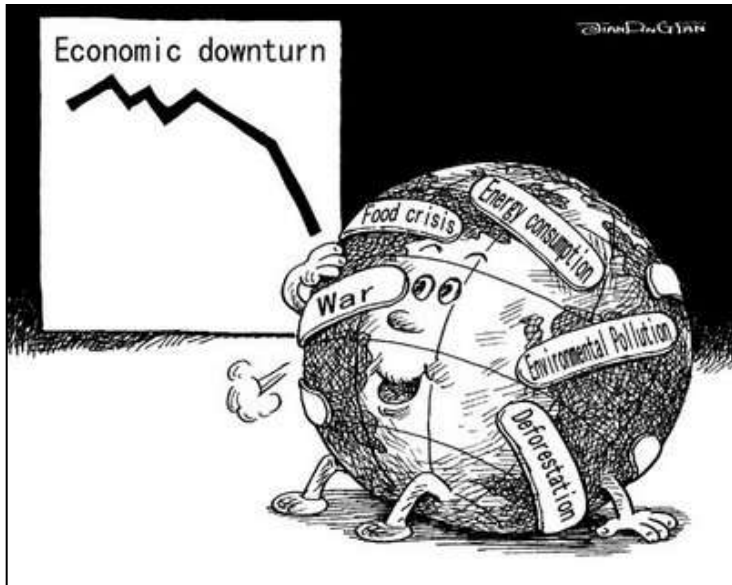
1. The impact of epilepsy from the patient's perspective, I: descriptions and subjective perceptions. Fisher RS et al (2000a) *Epilepsy Research* 41:39,51
2. WHO fact sheet on Epilepsy
3. Epilepsy in North America *Epilepsia*. 2006 Oct;47(10):1700-22. (ILAE conducted review)
4. CDC 2001 report on Texas Behavioral Risk Factor Surveillance System (BRFSS)

Conclusion Number 1.



“I am not alone.”

2. Problems: Economic – Jobs



- Its even tougher for people with epilepsy.
- They are much more likely to be unemployed.
- They are much more likely to be discriminated against.

2. Problems: Economic – Jobs

Epilepsia, 46(12):1978–1987, 2005
Blackwell Publishing, Inc.
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Employers' Attitudes to Employment of People with Epilepsy: Still the Same Old Story?

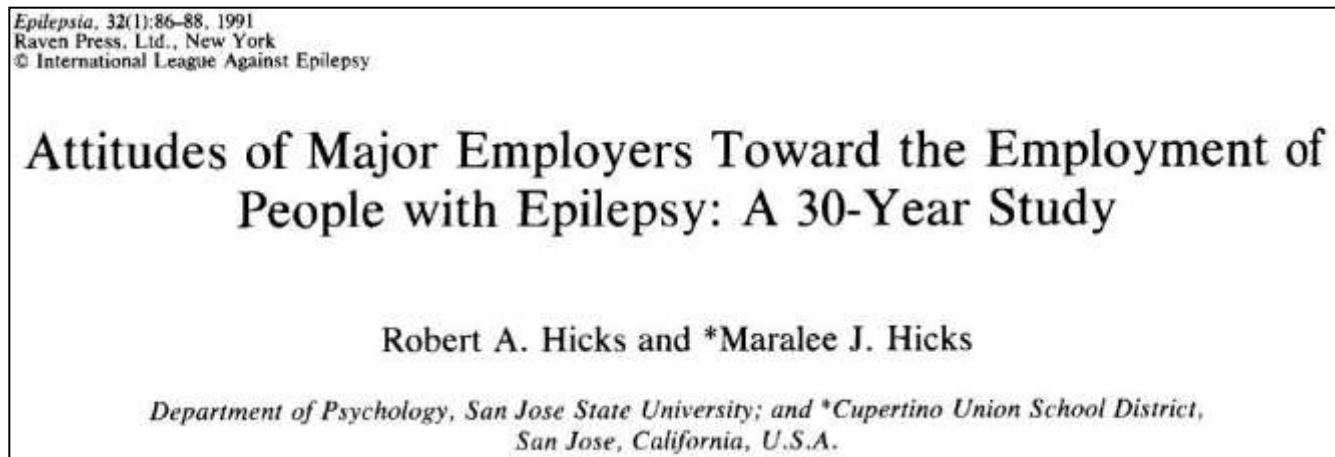
*Ann Jacoby, †Joanne Gorry, and ‡Gus A. Baker

**Division of Public Health, University of Liverpool, Liverpool; †Department of Clinical Psychology, Rathbone Hospital, Merseyside; and ‡Division of Neurosciences, University of Liverpool, Liverpool, U.K.*

- **204 companies in the UK**
- 1/5th - hiring people with epilepsy would be a “major issue”
- 1/5th - there were “no jobs for people in the company for people with epilepsy”

2. Problems: Economic – Jobs

Thankfully, things are a bit better in USA:



The number of companies who would willingly hire PWE:

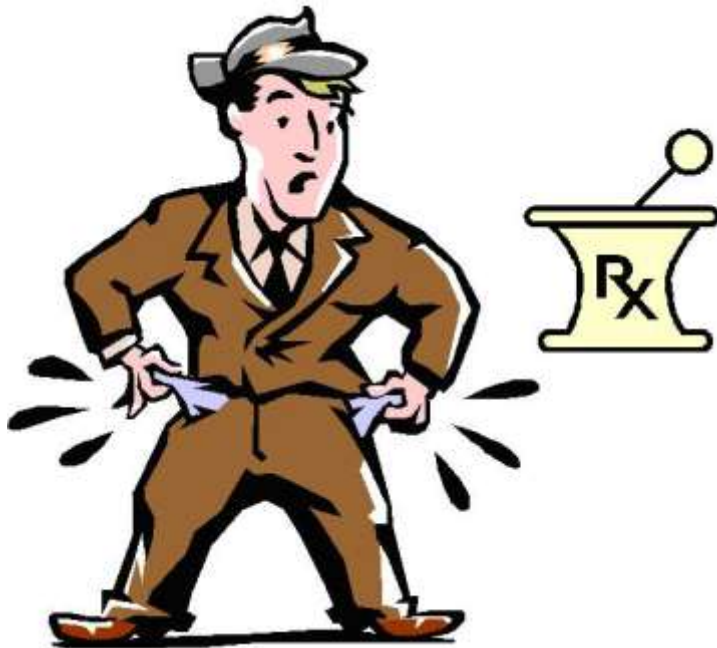
- In 1956 – 20%
- In 1986 – 95 % (Why not 100 % ???)

2. Problems: Economic – Jobs

Employers give many different reasons:

- Getting to work, especially if not driving
- Concerns about your safety if you have a seizure at work
- Worry about the company's liability
- belief that you have psychological problems or trouble thinking
- Fear that a seizure will scare off customers

2. Problems: Economic – Treatment costs



- Having epilepsy is expensive:
- 4,523 \$/year more expensive!
- Antiepileptics can be expensive!
- Injuries can be costly to treat
- It can be a vicious cycle, especially if you **need expensive meds to control your epilepsy!**

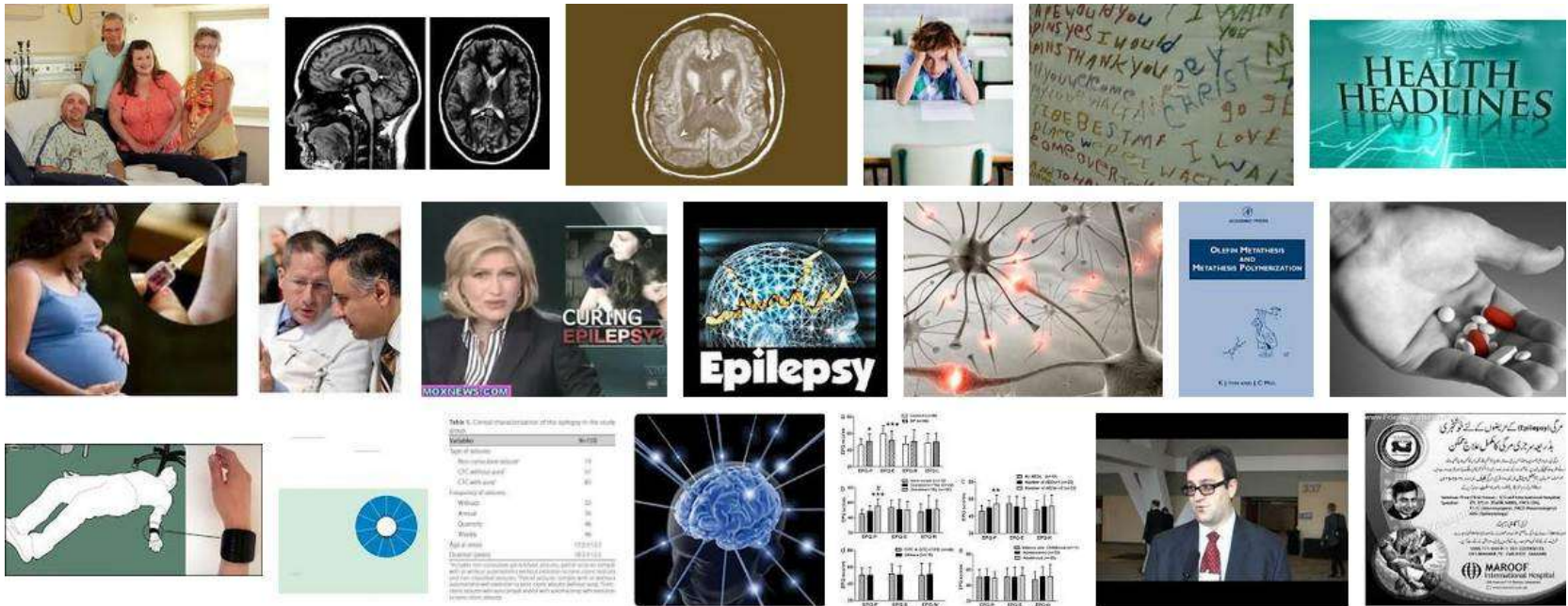
3. Problems: Social – Attitudes of others → self-image



- Epilepsy was (rather stupidly) considered an act of possession in the distant past.
- Public knowledge (and hence public perception) has improved
- Has it improved as much as it should?**
- Many patients are stigmatized by their diagnosis

3. Problems: Social – Attitudes of others → self-image

Public perception: My informal study - Images posted on google



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3. Problems: Social – Attitudes of others → self-image

Has public knowledge/perception improved as much as it should?

- Many people (22%) don't know whether epilepsy is contagious

- Many people think that all patients with PWE have severe seizures and are incapacitated by it (Jacobs et al 2006)
 - *Disability is defined as something that substantially limits one or more (not all) of the major life activities of such individual.*
 - ***Just because you are disabled does not mean you are incapacitated !!!***

3. Problems: Social – Attitudes of others → self image



Many patients are stigmatized by their diagnosis.

- This is partly (but not completely) because of public reactions to it.
- Talking about their epilepsy is a problem for a majority (>50%) of patients, especially adolescents.
- Greater stigma is associated with lower health-related quality of life, socioeconomic status, and need for special education.

(Westbrook 1996, Devinsky 1999)

3. Problems: Social – Driving and others



Some other problems you may face.

- People with epilepsy cannot drive unless their seizures are under control.
 - In California – 3 to 6 months

- Both epilepsy and the medications for it can cause thinking problems in some people.

- Partly because of this reason, sometimes its difficult to pursue higher education.

3. Problems: Summary

- Economic**
 - Jobs
 - Treatment cost
- Social**
 - Attitudes of others
 - Self-image
 - Education
 - Driving
 - Other concerns

Conclusion Number 2.

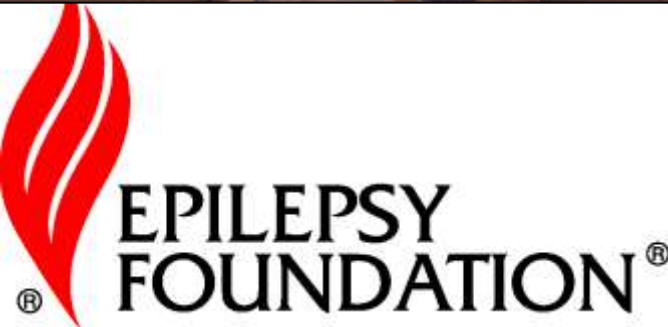


“I am not alone.”

“Many of the problems that I face are known”

How can I deal with these problems?

4. Solutions: RESOURCES



- You may not remember all of the resources available to you, and every person may require different kinds of help.

- Your three most important resources:
 - Your physician
 - A social worker (your physician can refer you to one)
 - A representative of the Epilepsy foundation (EF)
 - www.epilepsyfoundation.com
 - www.epilepsynorcal.com

4. Solutions: RESOURCES



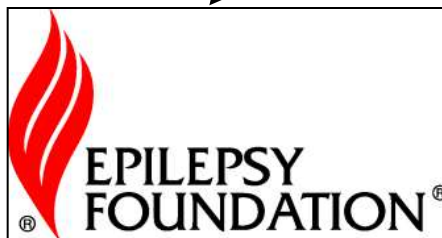
Ask your physician for a referral



Talk to the
Social worker



Counselor
Or
psychiatrist



Other resources

4. Solutions: RESOURCES

Other resources:

- A lawyer
- Patient support groups
- State human rights commission

25 Van Ness Avenue, Suite 800
San Francisco, CA 94102-6033
Maravie Bamba, Director
Tel: (415) 252-2500

- Equal opportunities commission

California Department of Justice, Equal Employment Rights & Resolution, (EER&R)
Office
1300 I Street
Sacramento, CA 95814
(916) 324-5482

It is best to seek guidance from a social worker, and the EF representative initially.

4. Solutions: RESOURCES



Ms. Jeannette Hilgert

MSW

SF VA Medical Center

4. Solutions: Economic – Jobs



American Disabilities Act (1990)

Not all patients with epilepsy qualify for disability.

- Substantially limits one or more of a person's major life activities
- substantially limiting some time in the past
- employer treats the individual as if it does.

4. Solutions: Economic – Jobs

During an interview, an employer *cannot* ask:

- whether she has epilepsy or seizures;
- whether she uses any prescription drugs; or
- whether she ever has filed for workers' compensation/was injured

After making a job offer, an employer may ask questions about an applicant's health and may require a medical examination.

- They need to make adjustments to the job requirements
- They may need to make other accommodations e.g. timed breaks

4. Solutions: Economic – Jobs

Title - 1



Job applicants with disabilities must **first**:

- Satisfy the required skill, experience, and education levels required for the position.
- Be able to perform the "essential job functions" with or without "reasonable accommodations"

Complaints to be filed within **180 days** with the ECOE (U. S. Equal Employment Opportunity Commission)

4. Solutions: Economic – Treatment cost

- “Service connected” – All treatment costs are covered.
 - Trauma while in service
 - Exposure to agent orange
 - Secondary side-effects of epilepsy medication e.g. osteoporosis

- If not service connected:
 - Talk to your social worker about SSI and other avenues.

3. Solutions – Social – Public perception and self-image



Public perception:

- Epilepsy awareness months
- Newspapers
- Epilepsy foundation
 - Changing public perception is a long and difficult process!
 - YOU CAN HELP!! Contact the epilepsy foundation.

3. Solutions – Social – Public perception and self-image

Self-Image:

- Counseling
 - We have an especially good counsellor at the SF VAMC: Gilbert Woo

- Participate in support groups
 - Identifying with other people with the same issues can be very helpful
 - In many ways, other people with epilepsy understand your problems the best
 - They may be able to suggest solutions others have not thought of.

- Bring depression and other mental health issues to the attention of your physician/counselor. Don't hide them.

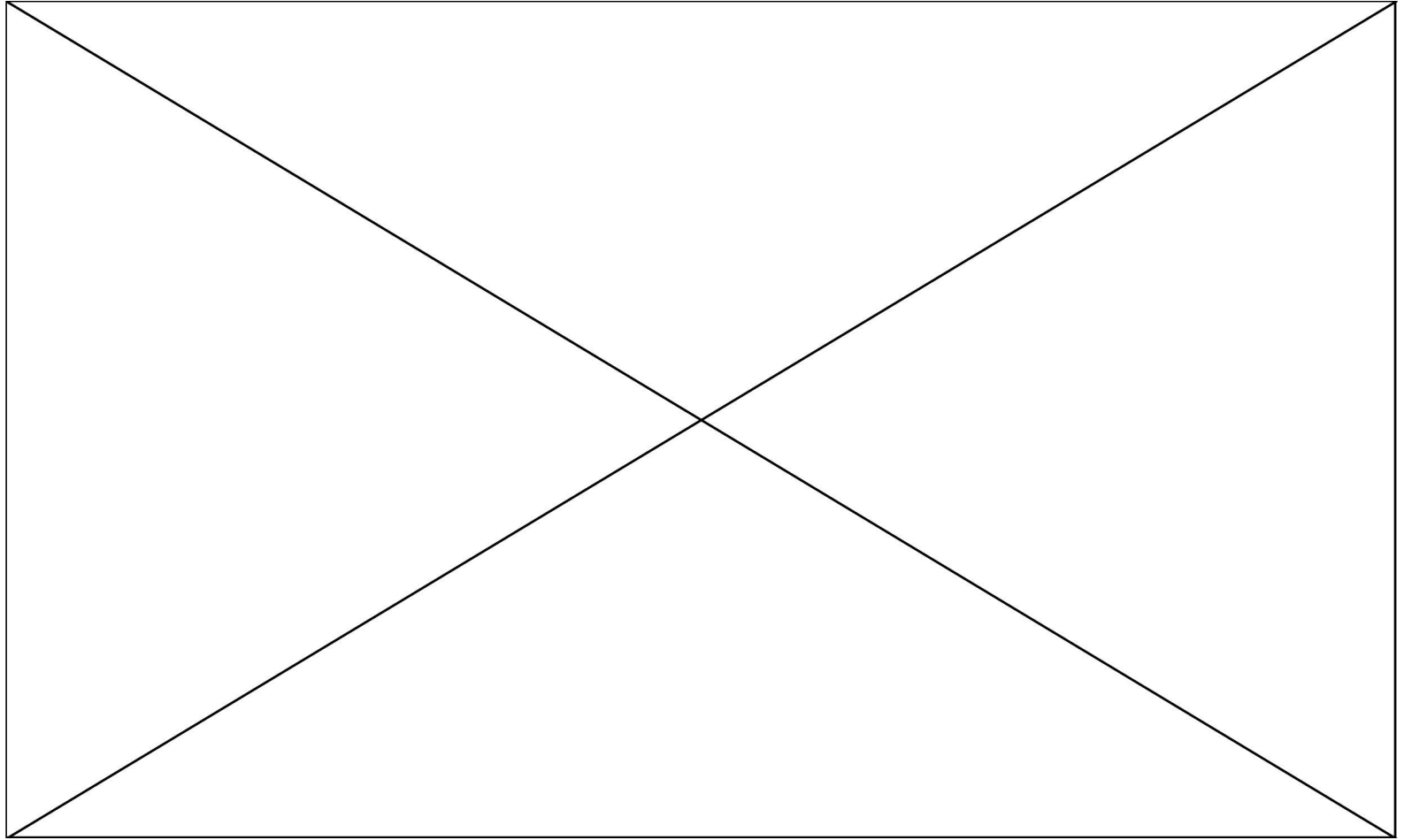
4. Famous people with epilepsy



- **People who overcame the “Social” issues:**
 - Pope Pius IX
 - Danny Glover
- **People who overcame the “Economic” issues**
 - Ronde Barber
 - Jonty Rhodes
- **People who overcame both!**
 - Julius Ceasar
 - Napoleon Bonaparte (*likely*)

My favorite cricket player, happens to have epilepsy

Jonty Rhodes



Conclusion: What I hope you're thinking

1. I am not alone
2. Many of the problems that I face are known
3. There is help. I will talk to my physician, social worker, and the epilepsy foundation and find such resources.
4. I deserve, and will have, a full, complete life.