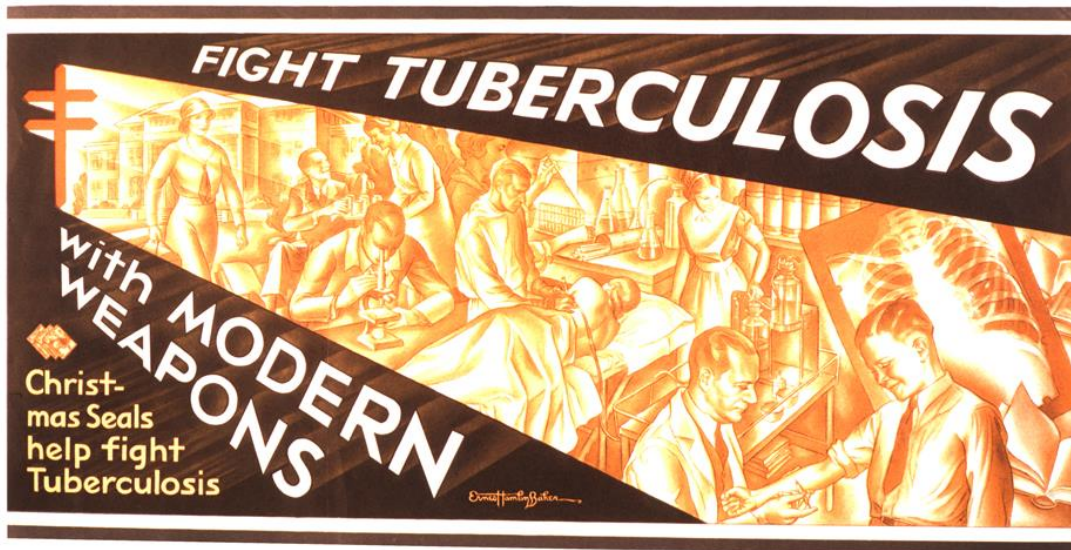


DISEASE CAMPAIGNS: SYNERGY, NOT COMPETITION

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CHARITABLE CRUSADES

- Twentieth-century campaigns against tuberculosis, polio, cancer, and heart disease
 - “I don’t always have a nickel sometimes to pay for my lunch at school... but I’m going to save some pennies all right to buy some of them Christmas seals with.”
 - March of Dimes: “the cheapest paid-up insurance policy you can get— only a dime.”



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 - March of Dimes: “the cheapest paid-up insurance policy you can get—only a dime.”
 - 77% of urban Americans donated to fight tuberculosis; 70% for polio
 - American Cancer Society, the National Foundation (polio), and the American Heart Association each had at least two million volunteers
- Universal claims, not about patients’ interests
 - “Unlike automobile clubs or veterans’ groups,” disease associations “cannot obtain new members from any clearly-defined segment of the population.”

PATIENTS AND FAMILIES COME TOGETHER

- National Multiple Sclerosis Society (1946)
 - Successfully pushes for neurological disease institute at NIH
- United Cerebral Palsy (1946)
 - “We can’t have this organization taken over by people who don’t see CP as we do. *We* are the ones with the CP children.”
- Arthritis Foundation (1948)
- Muscular Dystrophy Association (1950)

PATIENTS' GROUPS FACE SKEPTICISM

- “I was invited to chair a society of amyotrophic lateral sclerosis. Why not one for tuberous sclerosis... and still others for all the other myopathies and amyotrophies? Not so long ago a society for myasthenia gravis has come into being, for which there is little rhyme and less reason.”

(President of the American Neurological Association, 1958)

- “We don’t want colostomates making a social life out of being colostomates... we don’t want membership drives. We want people leaving us.”

(American Cancer Society vice president, 1976)

1970s: CHALLENGES TO MEDICAL AUTHORITY

- Health consumer movement
- Women's health movement
- Mental patients' rights
- Disability activism

FIGHTING AIDS

- Building on gay rights organizing
- From confrontational activism to fundraising galas



FIGHTING BREAST CANCER

- Women's health movement
- Following AIDS activists' example

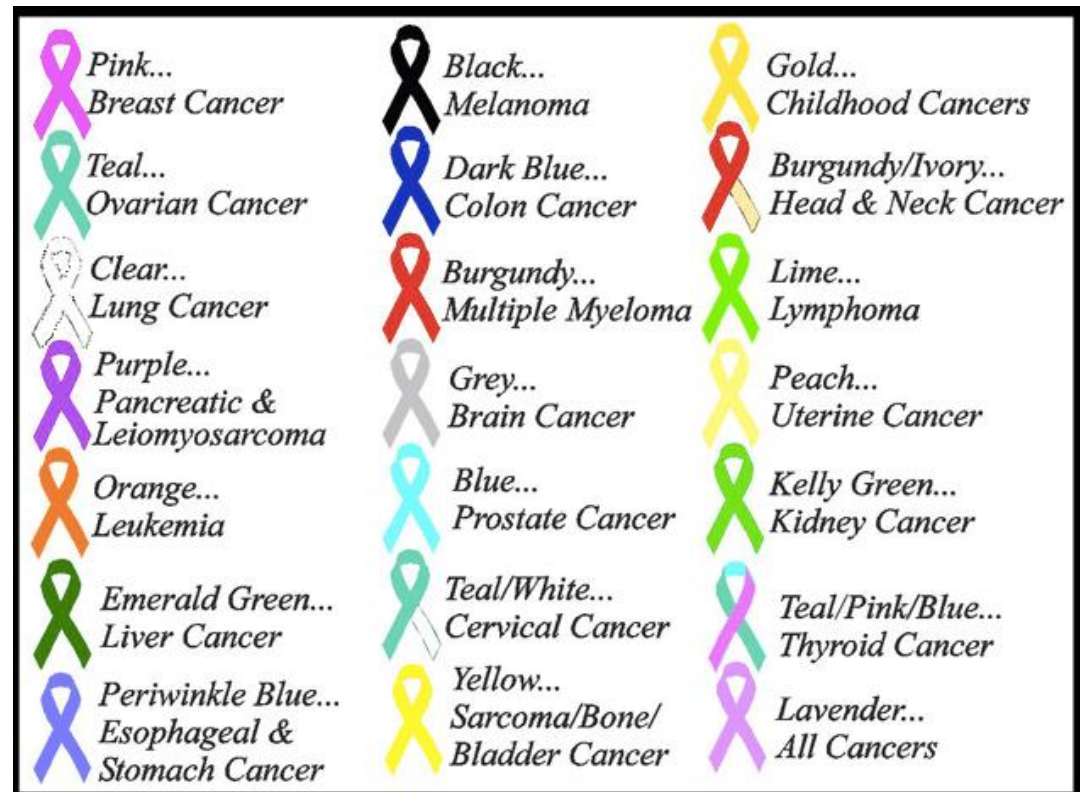


FIGHTING BREAST CANCER

- Women's health movement
- Following AIDS activists' example
- Political opportunities in the early 1990s
 - Post-Anita Hill, “a lot of male colleagues don't want to be on the wrong side of any women's issue” (Senator Tom Harkin)
 - “a chance for the Republicans to make some points with women. It is not an abortion issue.” (NBCC board member)

DISEASE CAMPAIGNS HELP EACH OTHER

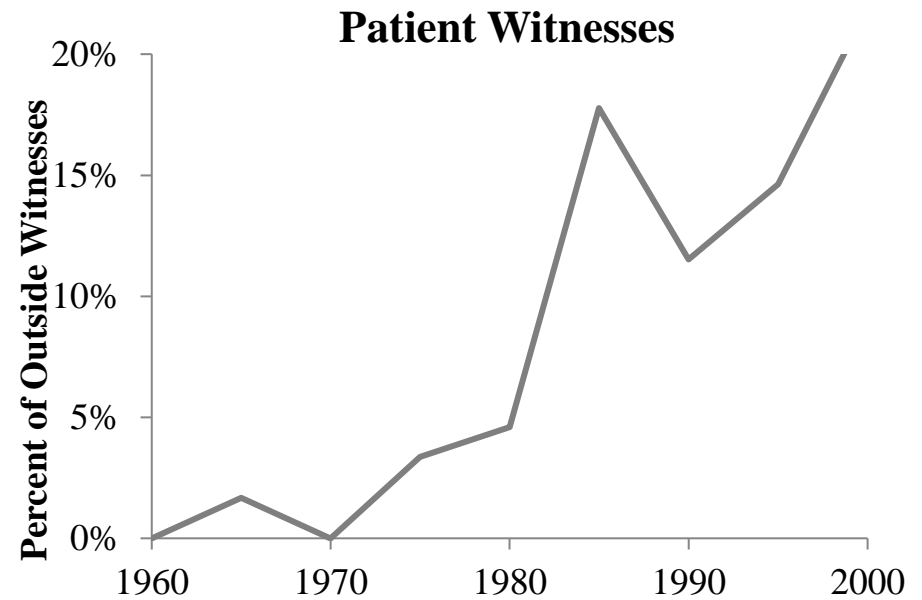
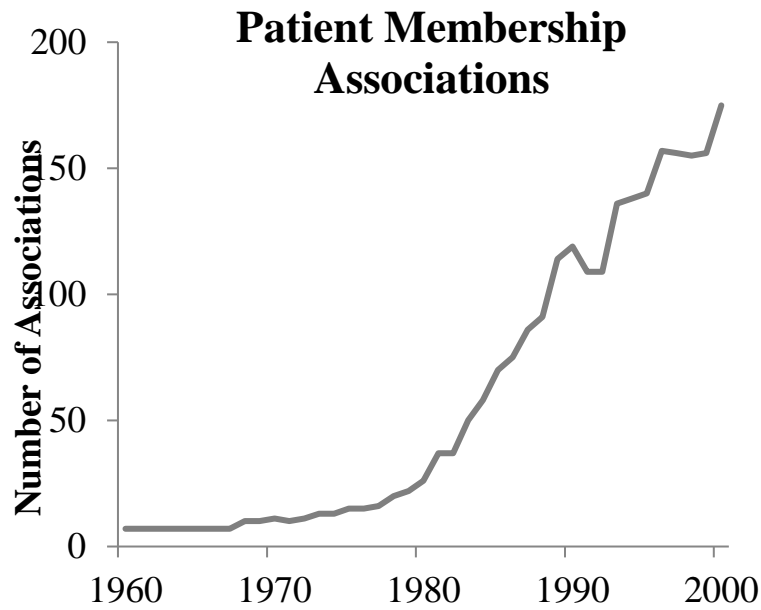
- Mimicry is a good strategy!
 - Ribbons, walks, etc.



DISEASE CAMPAIGNS HELP EACH OTHER

- Mimicry is a good strategy!
 - Ribbons, walks, etc.
- Legitimacy
 - Public perceptions, policymakers' responses
- Direct aid from one disease's advocates to another
 - Inspiration, assistance, training

GROWTH OF PATIENTS' ACTIVISM

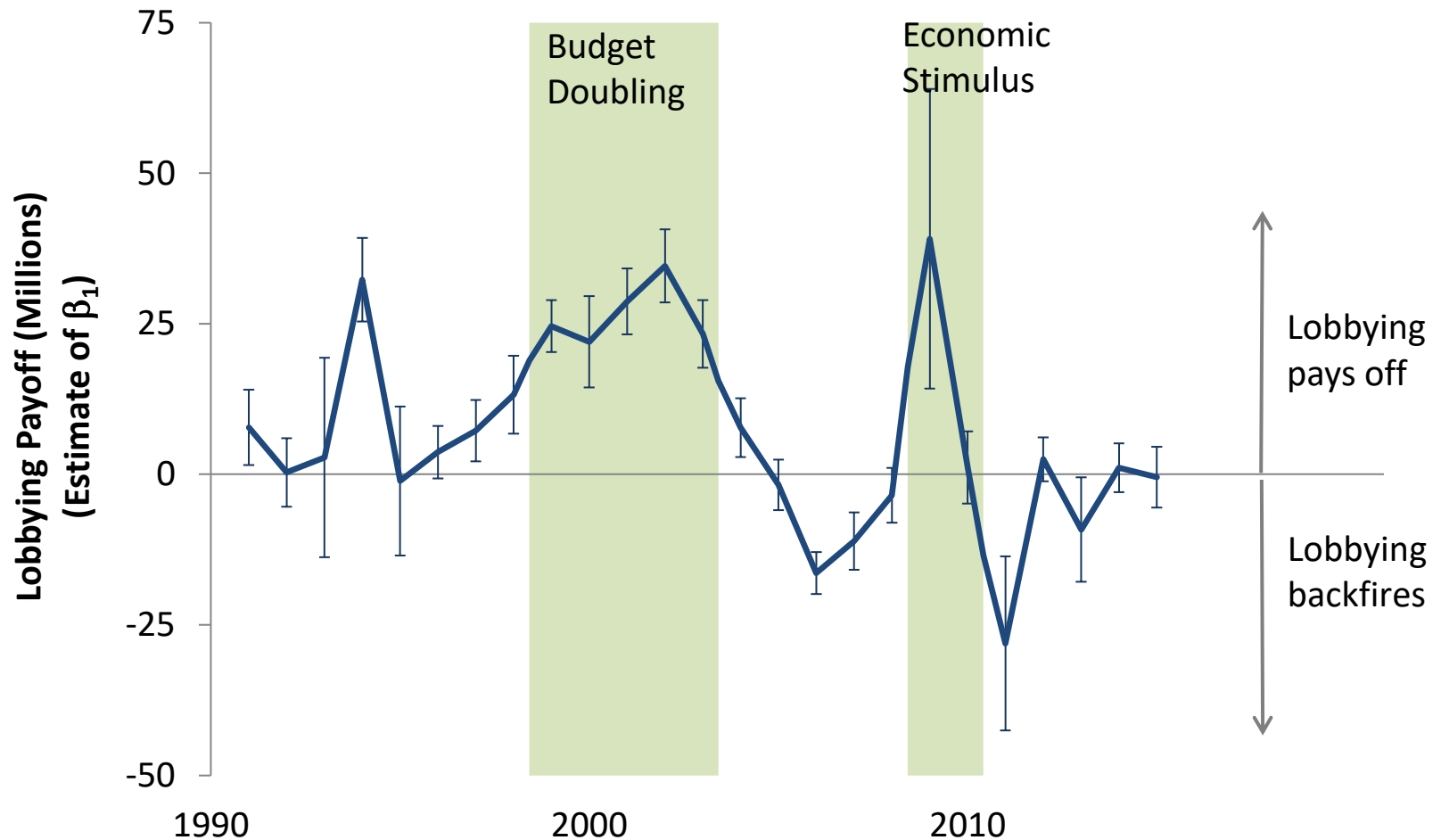


FEARS ABOUT DISEASE ADVOCACY

- **Zero-sum game**
 - “Specific advocacy efforts can succeed in gaining large increases for certain diseases (e.g., AIDS and breast cancer) at the expense of others” (Congressional Research Service, 1998)
- **Shrinking pie**
 - “The fighting between diseases, this ‘siblicide,’... could provoke ugly battles that result in NIH funding being cut overall” (Rep. John Porter, 1997)
- **Is money really taken from one disease to fund another?**
 - If we weren’t so focused on breast cancer, would migraine get more funding?

LOBBYING WORKS (WHEN THE BUDGET IS INCREASING)

$$DNIHDOD_{dy} = b_1Lobbying_{d(y-1)} + b_2DMortality_{d(y-1)} + c + \epsilon_{dy}$$



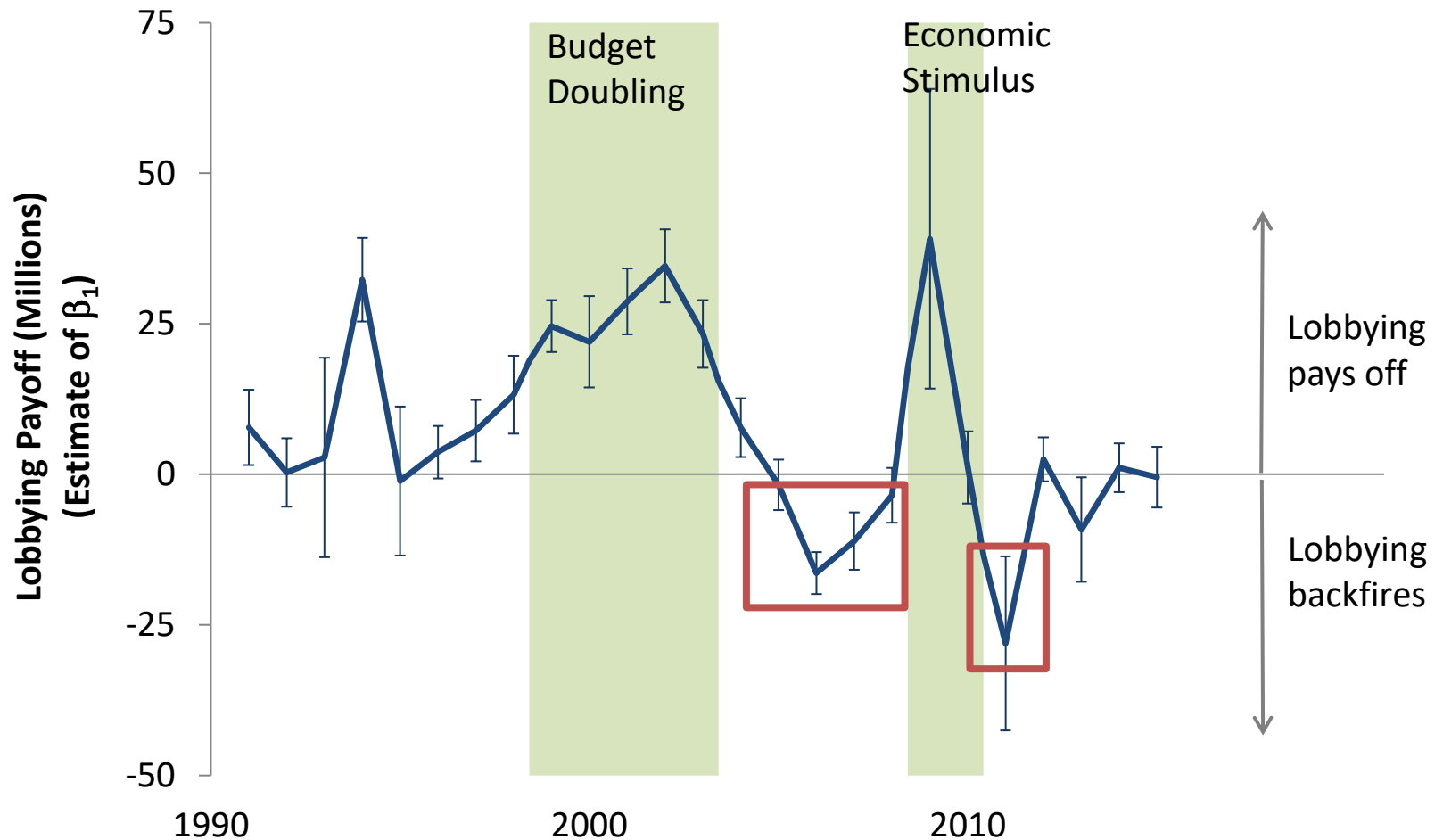
NIH CORRECTIONS

“I go to Center reviews, and the experts from the field are saying ‘this is very unlikely to yield substantive results,’ and Congress is telling me to fund it. And that hurts because I have in my back pocket a hundred good grants that I can’t fund.”

(NIH official responding to a large earmark for a single disease)

MOBILIZED DISEASES FARE WORSE IN SUBSEQUENT YEARS

$$DNIHDOD_{dy} = b_1Lobbying_{d(y-1)} + b_2DMortality_{d(y-1)} + c + \epsilon_{dy}$$



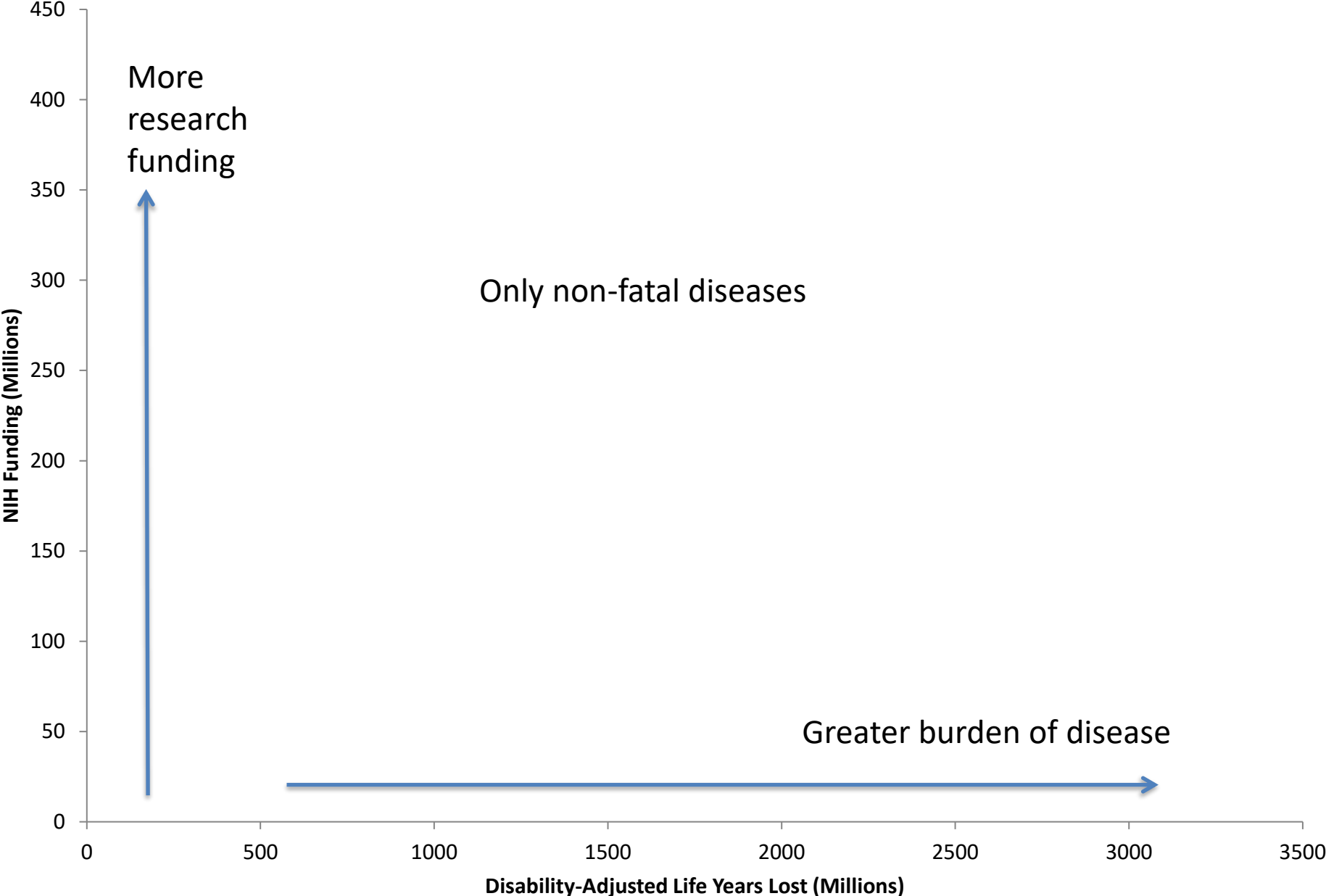
ADVOCACY IS NOT ZERO-SUM

- One disease's gains rarely come at another disease's expense.
- Disease campaigns helped the NIH budget grow.
- Budget corrections may mean spillovers across disease categories.

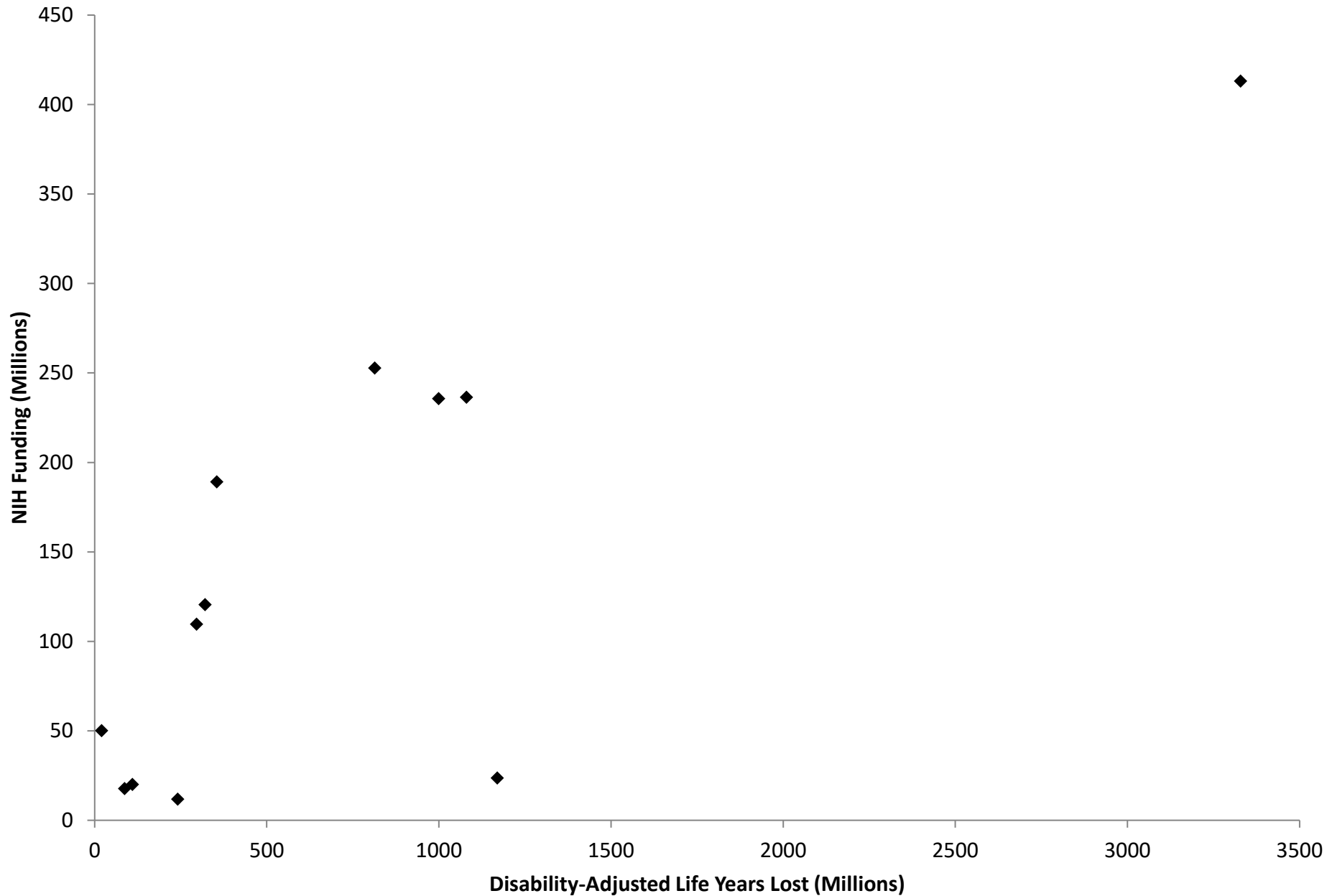
LESSONS FOR ADVOCATES

- Don't assume diseases are in competition
- Learn from advocates for other diseases
- Ask for advice and training, share strategies
- But still organize around a single condition

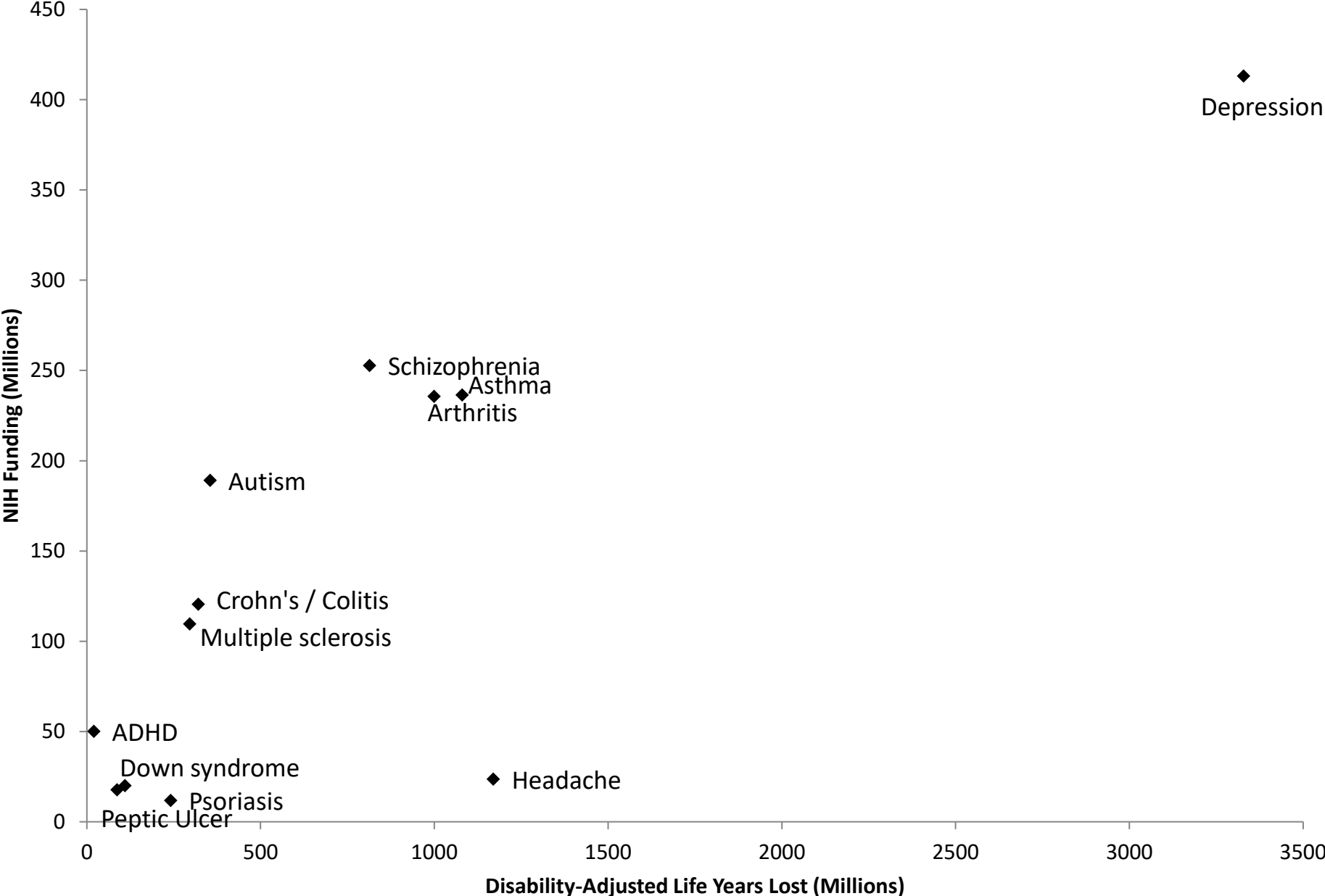
UNEQUAL GOVERNMENT FUNDING



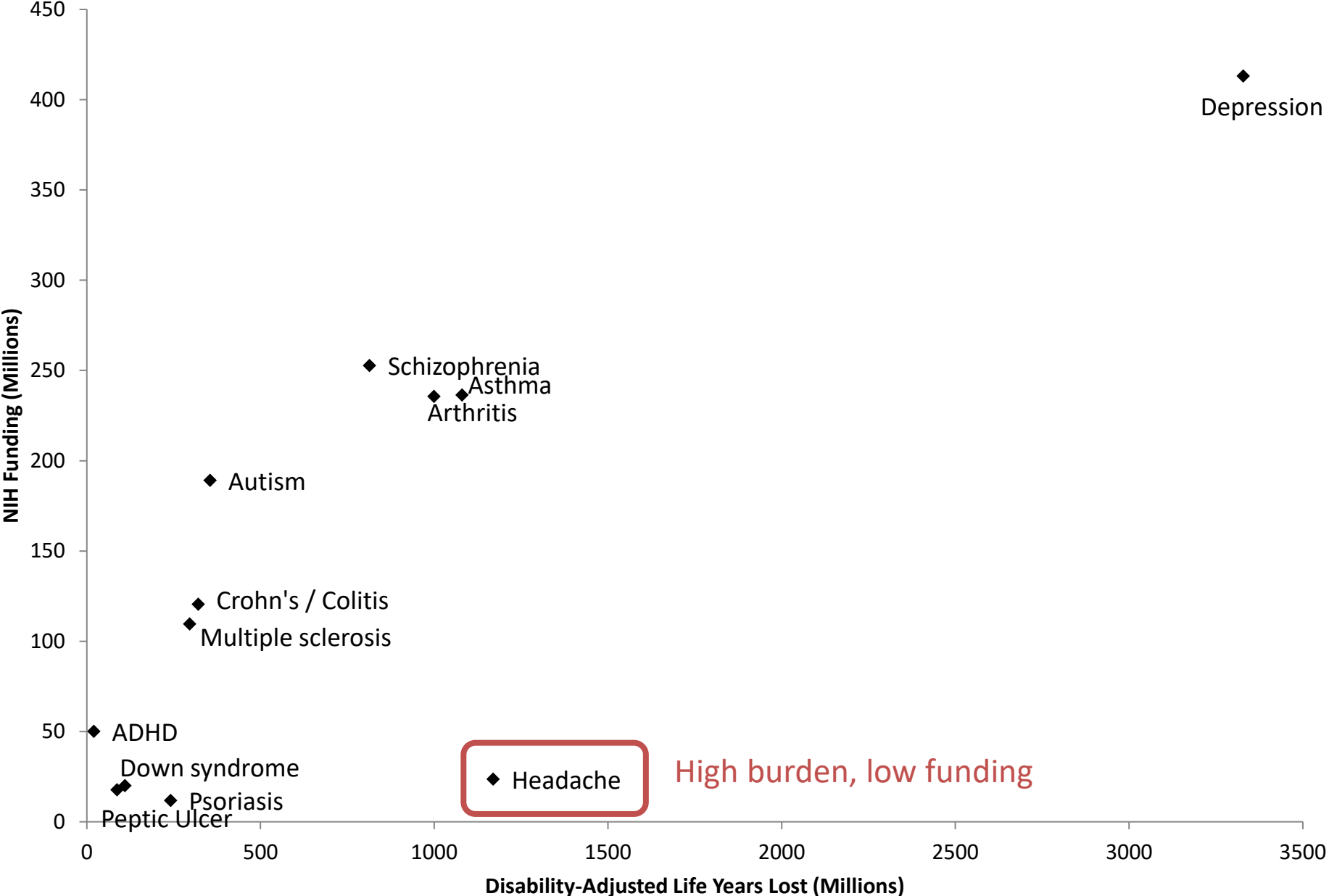
UNEQUAL GOVERNMENT FUNDING



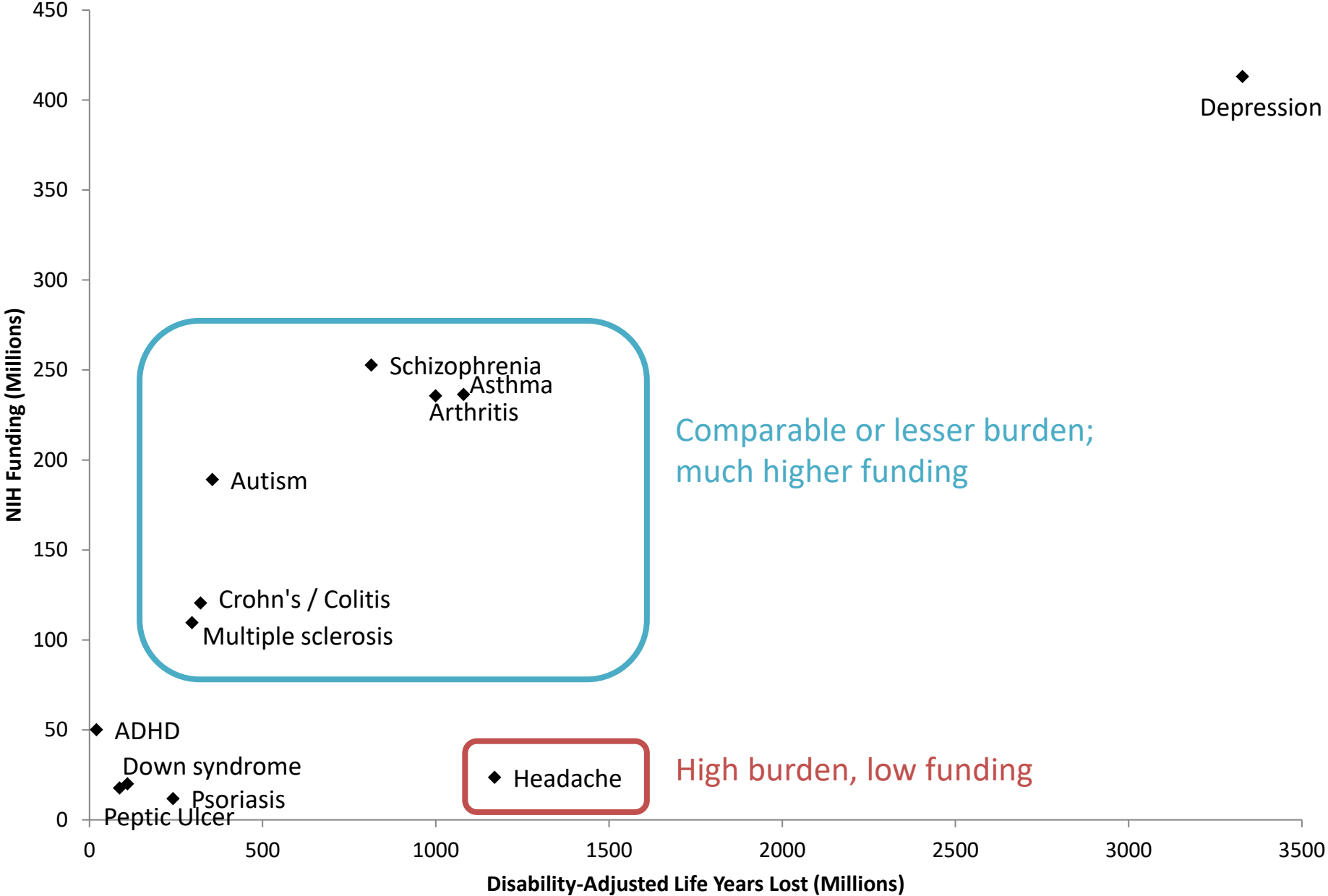
UNEQUAL GOVERNMENT FUNDING



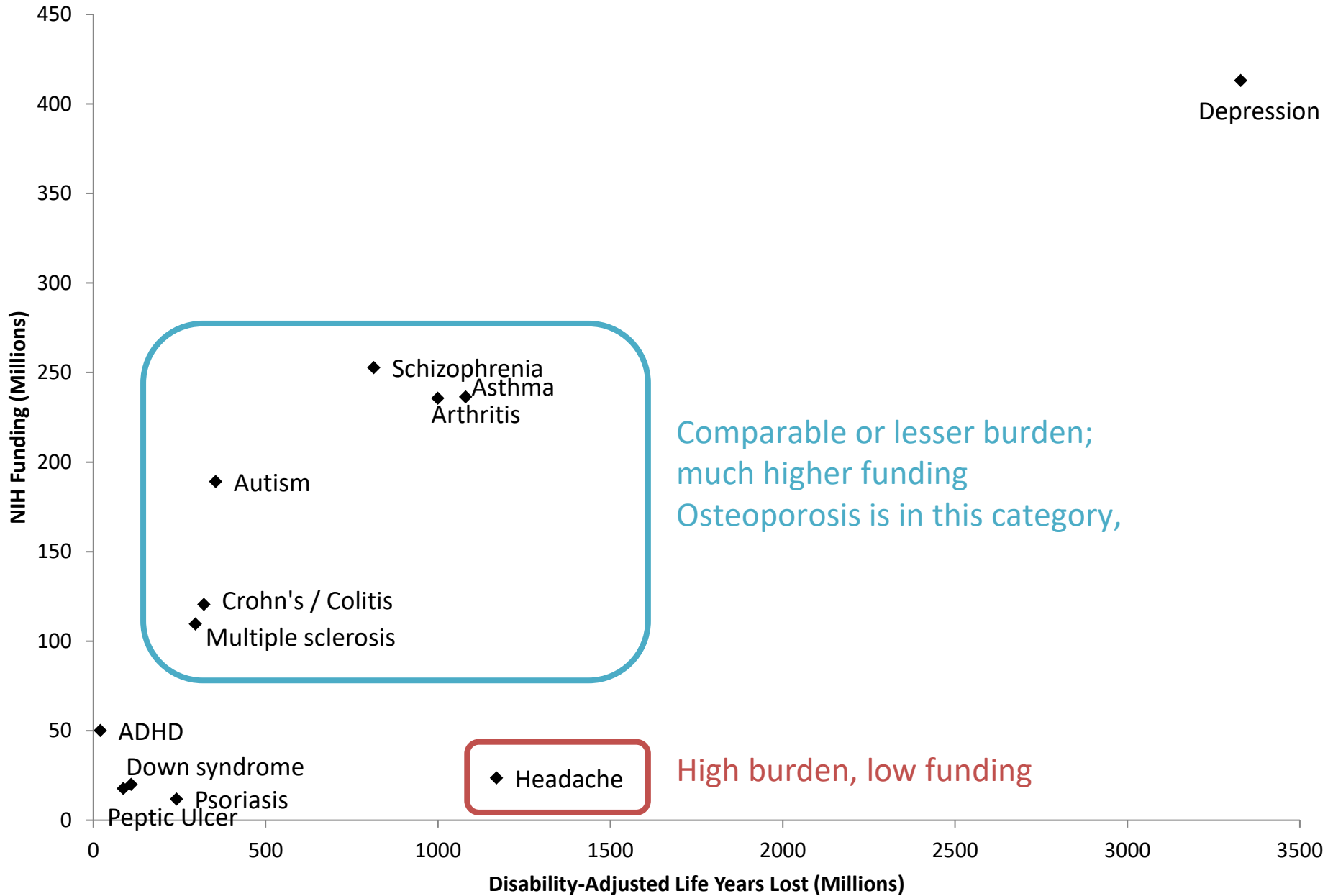
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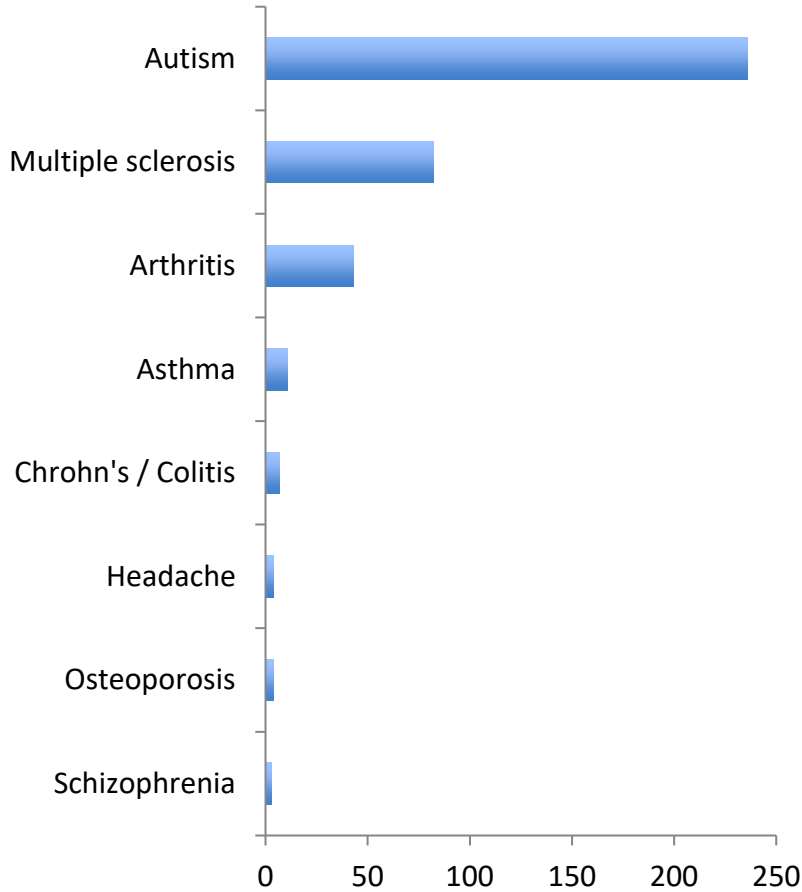


UNEQUAL GOVERNMENT FUNDING

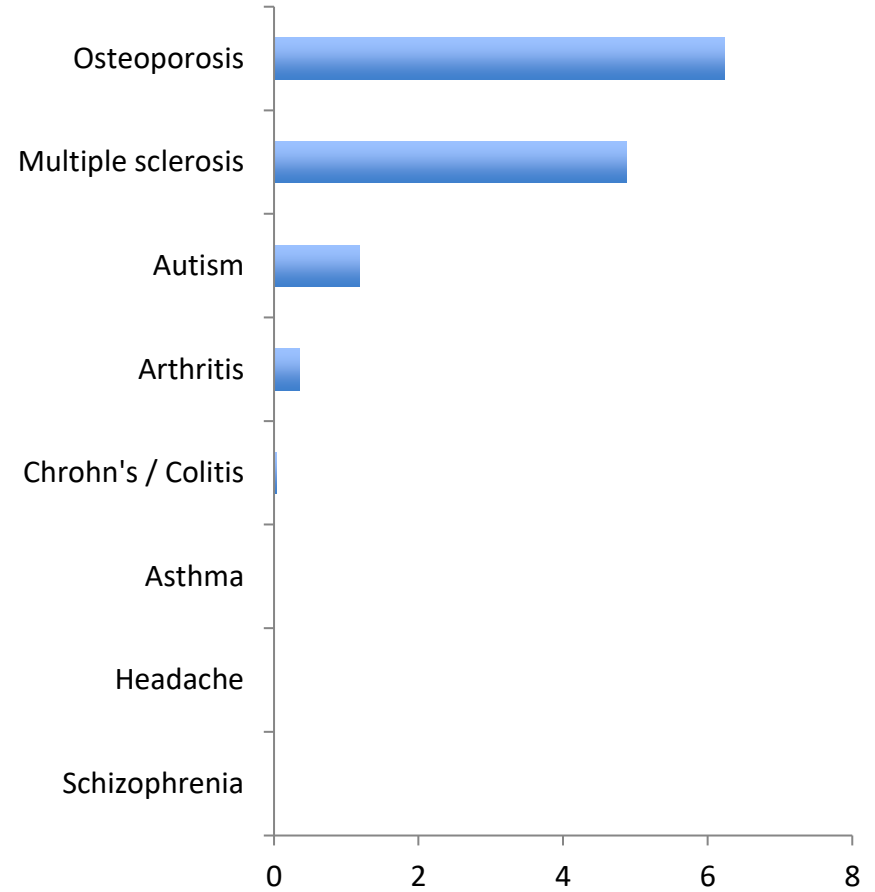


CAN ADVOCACY EXPLAIN THE FUNDING GAP?

Nonprofits

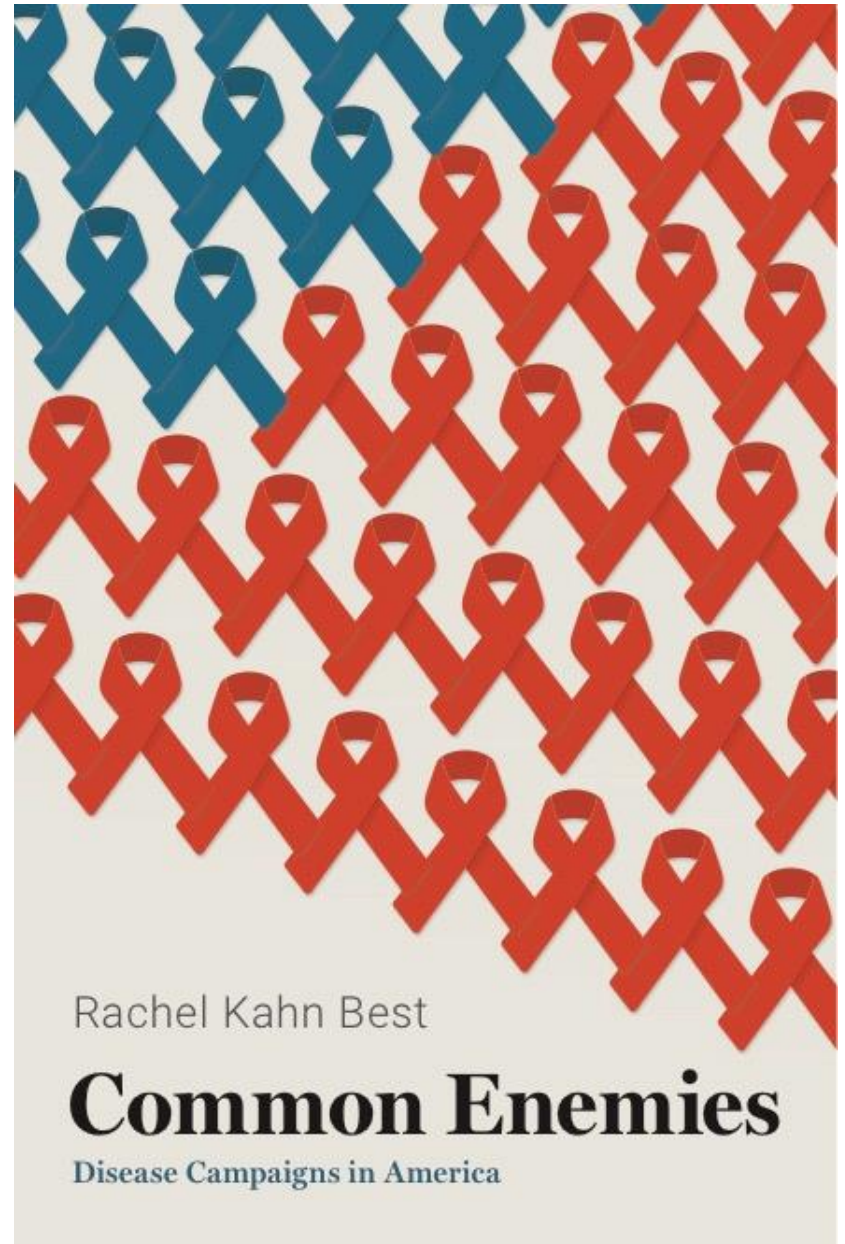


Lobbying (millions)



THANK YOU

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QUESTIONS

- What diseases might be useful models for migraine advocacy?
- What's an organization you could reach out to for advice?
- What questions would you ask an experienced advocate?