Gender Disparity in the Funding of Diseases by the US National Institutes of Health

Arthur A Mirin, PhD

August 2023

Our analysis of NIH funding shows:

- **There are roughly 3 times as many diseases whose NIH funding pattern favors males, as there are diseases whose funding pattern favors females**

- **The degree of over- or under-funding for diseases whose funding pattern favors males is nearly twice as great as that for diseases whose funding pattern favors females**

Applied mathematician to health advocate

- Developed advanced computational models for simulating climate over most of career (retired in 2013)
- Became involved in advocacy for myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) in 2016
- Performed NIH funding versus disease burden analyses; publications in 2016, 2020 and 2022
- Observed anecdotally that lowest funded diseases tended to be those that affect more women
- Analyzed NIH funding with respect to gender; published results in Journal of Women's Health (2020).

Disease burden is used to normalize funding when comparing diseases

- **Prevalence (i.e., dollars per patient) is insufficient; ignores impact of disease**
- **Burden considers not only prevalence, but morbidity and mortality**

The Disability Adjusted Life Year (DALY) is used to measure disease burden

$$DALY = YLD + YLL$$

$$YLD = P * DW$$

$$YLL = N * L$$

P = prevalence

DW = disability weight (0 to 1)

N = number of deaths

L = number of years lost per death

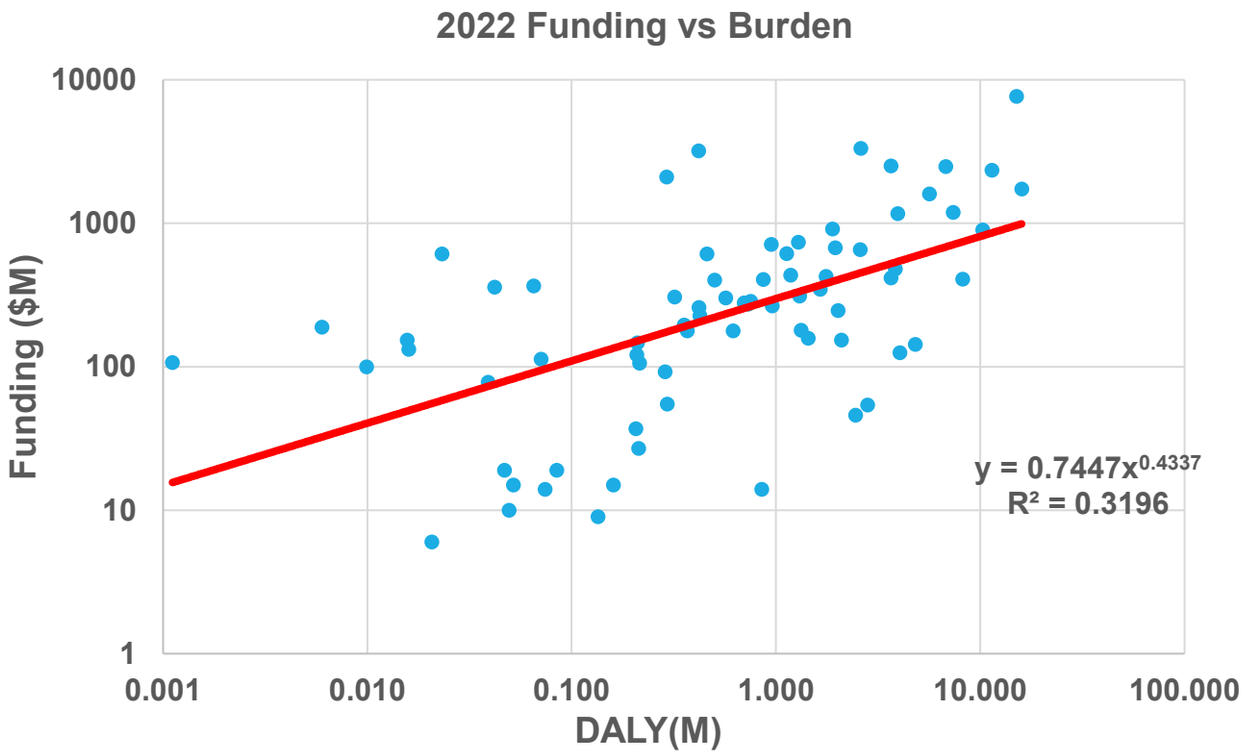
DALY is utilized by the World Health Organization

Note: economic burden not included

We utilize funding and burden data provided by NIH

- The most recent data at the time of our 2020 journal article used 2015 burden and 2019 funding
  - An update using 2017 burden and 2022 funding has recently been performed
- NIH-provided data covers roughly 25% of those diseases listed in the NIH Research, Condition and Disease Categorization (RCDC) portfolio

A regression analysis of 2022 funding versus 2017 burden is shown below



A disease is categorized as over (under) funded if its funding point lies above (below) the regression line

We compute power law least squares fit of funding versus burden

- Funding and burden vary by 4 orders of magnitude

- The power law fit is equivalent to linear least squares fit of log(funding) vs log(burden)
  - $y = a * x^b \Rightarrow \log y = \log a + b * \log x$

The regression curve is a straight line in log-log space

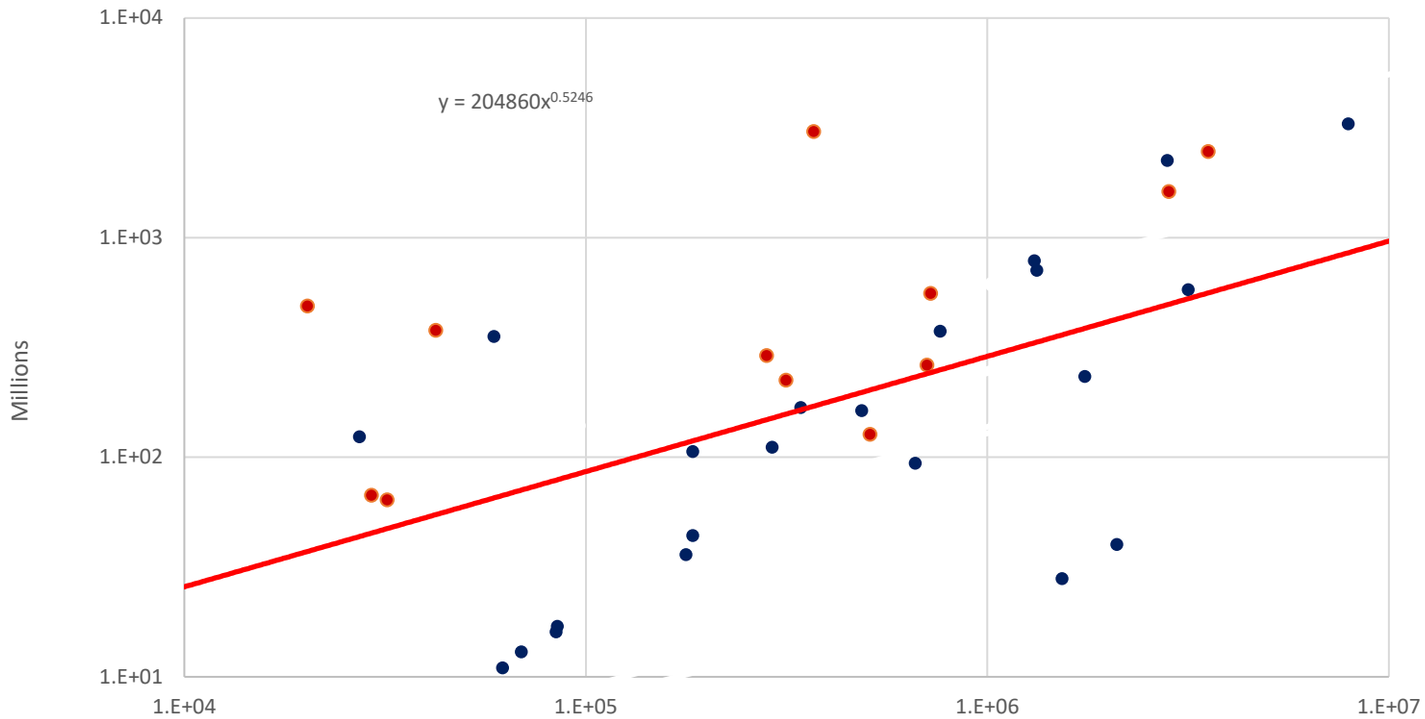
Diseases are categorized according to gender prevalence

- We include the 73 diseases whose funding and burden are covered by the NIH dataset, plus ME/CFS (for which we have funding and burden information)
- A disease is female (male) dominant if at least 60% of those affected (in the US) are female (male)
  - Other diseases are considered gender neutral
- We identified 23 female-dominant diseases and 12 male-dominant diseases among the 74 diseases included in our analysis

A funding/gender analysis demonstrates gender disparity

Male dominant – red dots
Female dominant – blue dots

2019 funding vs
2015 burden



A funding/gender analysis demonstrates gender disparity

- **Female dominant: 14 underfunded and 8 overfunded**
- **Male dominant: 1 underfunded and 11 overfunded**

- ***Male-favored* funding pattern – 25 diseases**
- ***Female-favored* funding pattern – 9 diseases**
- **Of gender-favored diseases, 74% favor males**

The extent of favoritism ALSO favors males

- **The degree of over/under-funding of *female-favored* diseases is approximately 2.8.**
- **The degree of over/under-funding of *male-favored* diseases is approximately 5.2.**

- **Not only are there roughly 3 times as many diseases whose funding pattern favors males, but the degree of favoritism is nearly twice as great**

The variation over time has been miniscule

- **Our published results of 2015 funding vs 2015 burden, 2017 funding vs 2015 burden, and 2019 funding vs 2015 burden, together with our unpublished result of 2022 funding vs 2017 burden, show very little variation in the degree of gender disparity**

Results of this analysis extend to the full NIH portfolio

- This 74 diseases in this analysis represent only one-quarter of the diseases in the RCDC categorization

- A chi-squared / P analysis gives a P value of 0.015, suggesting that these results can be extended to the full portfolio

Women's health has historically been marginalized and stigmatized

- The concept of hysteria goes back thousands of years and still persists
- Women are often told that the problem is in their head
- Anecdotally, many women have complained of not being taken seriously when reporting Long COVID

This has led to chronic underfunding of diseases affecting primarily women

The NIH funding process is not designed to address inequities

- NIH generally funds proposals, not diseases
- Under-researched diseases are at a disadvantage when competing against ‘established’ diseases
  - Reviewers tend to favor established methodologies/personnel, as they are perceived to have a higher probability of obtaining bang for the buck – plus reviewers are more familiar with them
  - NIH allocates miniscule funds for hypothesis generation

NIH does not heavily weigh burden in funding decisions

- **NIH claims to consider scientific merit, scientific opportunity, portfolio balance and budgetary considerations**
- **"Generally we look at the public health burden and it is a very-well-established way to do that. We also look at scientific opportunity because it's not going to be successful to throw money at a problem if nobody has an idea about what to do about it. We look at what our peer review process is telling us about the excellence of the science." (Francis Collins, 2015, Senate Appropriations Committee)**

How might NIH fix this gender inequity?

- The inequity can be partially measured using the RCDC funding analysis
- NIH can consider setting aside funds specifically for proposals oriented toward female-dominant diseases or apply additional evaluation points to proposals likely to help diminish the gender disparity

Has NIH taken any steps to fix this inequity?

- **NIH has acknowledged awareness**
  - **“Thank you for sharing this most important publication by Arthur Mirin titled “Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health”. We are aware of this publication and the insights presented therein. These insights will be considered as NIH develops strategies to overcome this disparity.” (from Eddie Billingslea, Office of Research on Women’s Health, to Bobbi Ausubel, advocate, 12 December 2020)**
- **I am not aware of steps taken to date**

References

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