

Lorraine Johnson, CEO, LymeDisease.org, Pl MyLymeData NASEM June 29, 2023

Patients need treatment options now



We need urgency in finding treatments and trialling treatments that are closer to cures than Band-aids.



There are millions of patients who desperately need well designed, accessible trials testing therapeutics that are of priority to the community. Excuses of no definitive biomarker or murky endpoints are not acceptable.



LymeDisease.org

The traditional pace of research is glacially slow. Patients who are sick are not waiting. Patients actually try different things. And they will proceed down this road...until they find something that works..."

Ezekiel Emanuel, University of Pennsylvania, Advisor Obama & Biden.

"If you don't have the pathobiology figured out, you try things. You don't just slow, slow, slow, walk it,"



https://www.statnews.com/2023/04/20/long-covid-nih-billion/

REVIEW ARTICLE

THE CHANGING FACE OF CLINICAL TRIALS

Jeffrey M. Drazen, M.D., David P. Harrington, Ph.D., John J.V. McMurray, M.D., James H. Ware, Ph.D., Janet Woodcock, M.D., Editors

Evidence for Health Decision Making — Beyond Randomized, Controlled Trials

Thomas R. Frieden, M.D., M.P.H.
N Engl J Med 2017; 377:465-475 | August 3, 2017 | DOI: 10.1056/NEJMra1614394

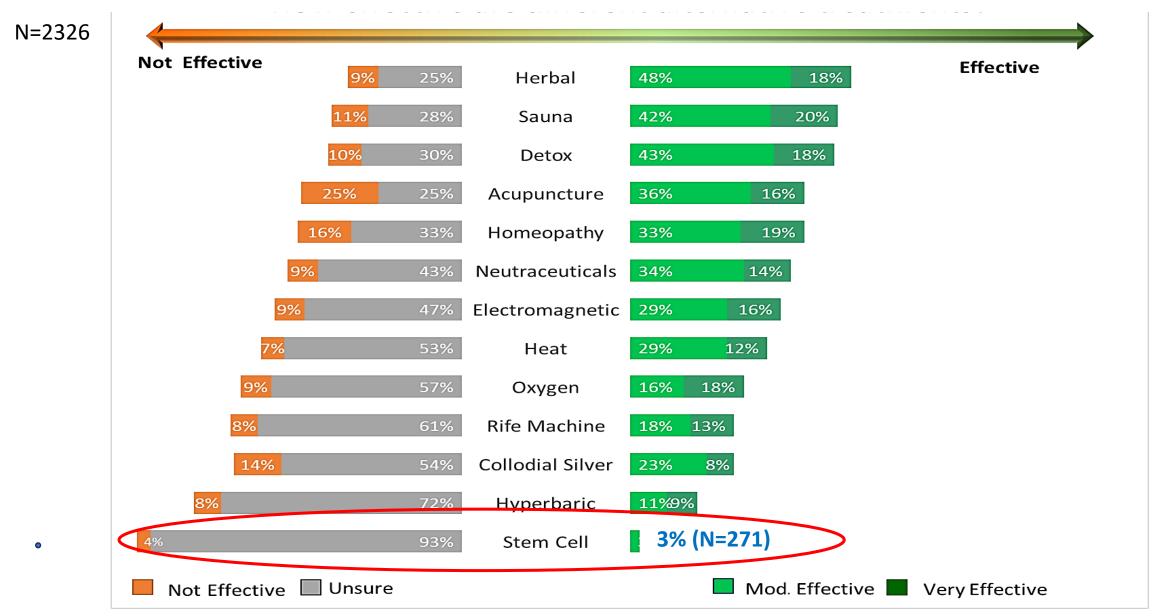
The gold standard of medical research is no longer enough and is not always the best evidence. We need to use all types of evidence including data from clinician practices and patient registries.

There will always be an argument for more research and for better data. But waiting for more data is often an implicit decision not to act, or to act on the basis of past practice rather than on the best available evidence.

Glorifying RCTs above other approaches, even when these other approaches may be either superior or the only practical way to get an answer, relegates patients to receiving treatments that aren't based on the best available evidence.

Frieden, 2017

What are the most effective alternative treatments?



Phase 1 Data Set, MyLymeData (November 2016)



"The future is already here – it's just not evenly distributed.

The Economist, December 4, 2003"

- William Gibson



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