

ME/CFS Clinician Coalition Survey

Interagency ME/CFS Working Group
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Background on the ME/CFS Clinician Coalition

- The ME/CFS Clinician Coalition has 21 members who have collectively spent hundreds of years treating many thousands of people with ME/CFS.
- The members are a mix of internists and a few different subspecialties. Less than half have clinics in academic centers. Three are already retired and a number are approaching retirement age, an important fact to keep in mind in thinking about what needs to be done to address clinical care for ME/CFS
- The ME/CFS Clinician Coalition's goals are to document their best practices, to educate the medical community, and to provide clinical insight to research.
- To advance the clinical care goals, the Coalition has developed consensus statements and recommendations, deployed a website for medical providers, and prepared a manuscript for publication on diagnosis and management.
- Coalition members are also involved in research as the clinical partners and have also undertaken a number of educational efforts
- The ME/CFS Clinician Coalition website is <https://mecfscliniciancoalition.org/>

Bottom Line

We have a problem with access to basic medical care that can't be fixed without your leadership and that of key medical associations

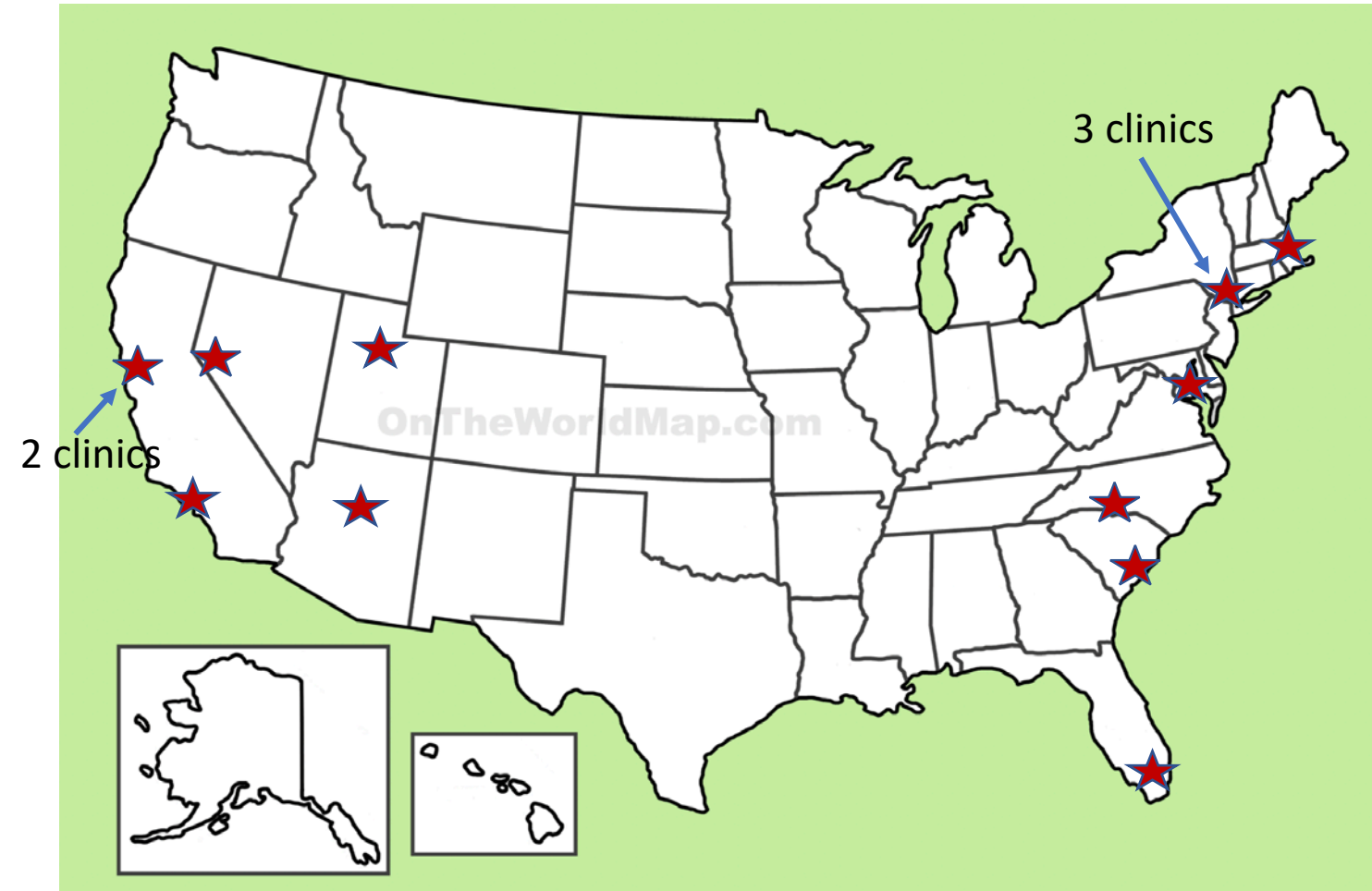
US ME/CFS Patient Population

- 1–2.5 million Americans
- All ages, races, socioeconomic groups
- 25% homebound or bedbound, as many as 75% can't work
- Yearly economic impact \$18–24 B (IOM) or up to \$51B (recent study)

COVID could quickly double the prevalence of ME/CFS

Main ME/CFS Specialist Clinics

For 1-2.5 M Americans



ME/CFS Clinics

< 15 active clinics

< 20 active ME/CFS clinicians

Many are nearing retirement

Patients seen at 7 of these clinics (1)

- 74% female
- 95% white, adult
- 95% have insurance
- 75% not working

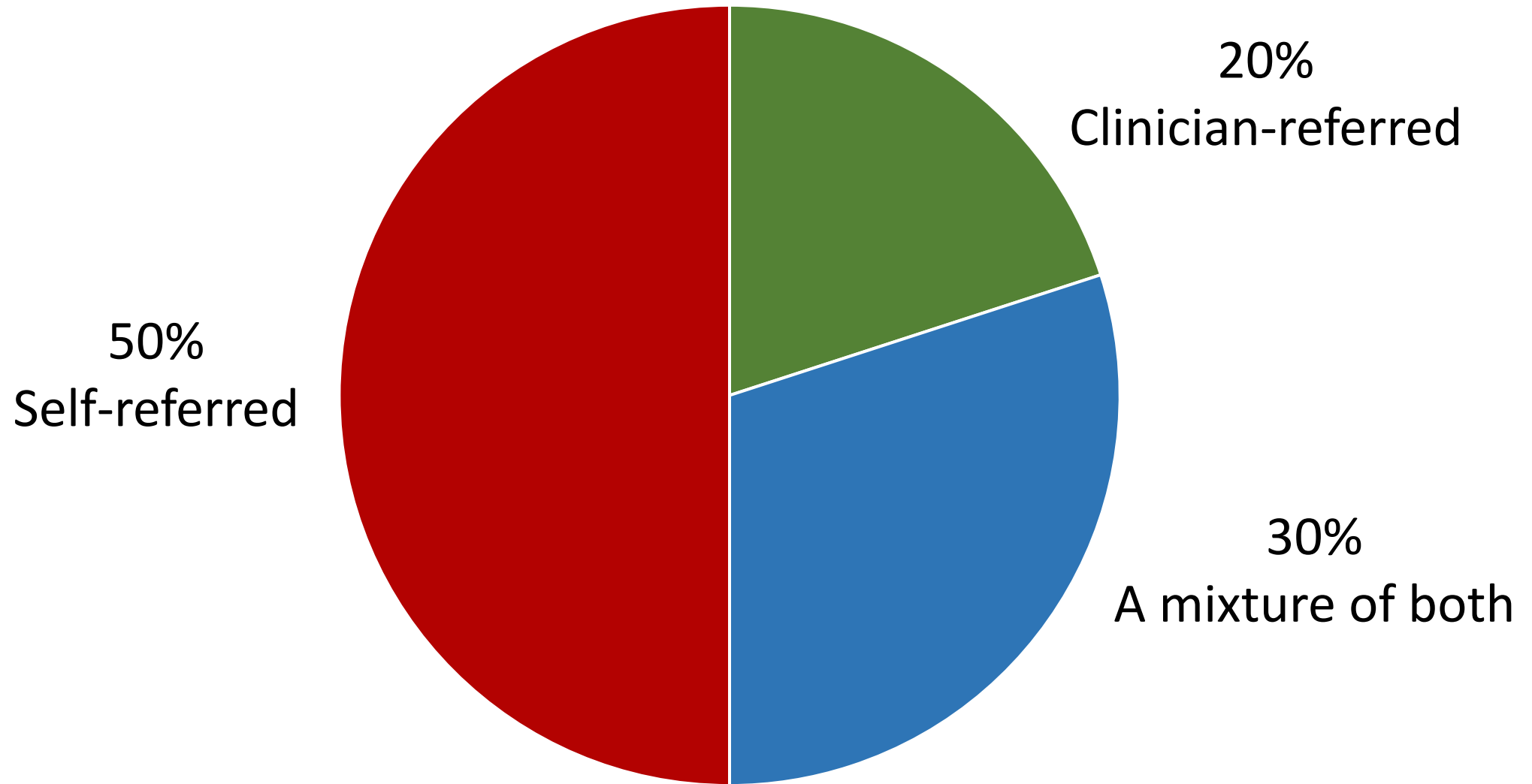
Note: The most severely ill rarely travel to these clinics and are not seen by local doctors

1) As reported in the CDC multisite study of 7 of these clinics

Clinician Coalition Survey Questions

Category	Question
Source of patients	<ul style="list-style-type: none">• Clinician or self-referred?
Insurance reimbursement	<ul style="list-style-type: none">• Do you accept. If not, why not?• Challenges with reimbursement? How address?
Engaging clinicians in patient care	<ul style="list-style-type: none">• Challenges with attracting clinicians to join their practices• Willingness of PCPs and specialists to collaborate in care of their patients• Barriers to increasing number of PCPs, specialists, ME/CFS experts
Educating the medical community	<ul style="list-style-type: none">• Use of onsite rotations for med students, residents, practicing physicians• Types of educational information provided to their patients' providers• Other approaches to teaching clinicians
What's needed	To increase the number of clinicians willing and able to provided needed care

Source of Referrals



Insurance Coverage/Reimbursement

Clinician time is not reimbursed

- Complex patients require long visits
 - 2 hours or more for initial visit
- Significant additional time for e.g., records review, appeals, disability, etc.
- Accept insurance?
 - No: 50% Yes: 21% Medicare: 21% Insurance + concierge: 8%

Tests, treatments poorly covered, require time-consuming appeals

- Even basic tests and treatments may not be covered
- Lack of evidence makes it easy to deny
 - Can spend hours on appeals which can take weeks to months
- Specialists and tests referred out may get better coverage
- Coding comorbidities can improve reimbursement

Lack of private and government reimbursement impedes ME/CFS clinical care by *any* medical provider, not just these experts

Engaging the Medical Community

Challenges in engaging specialists, PCPs in patient care

Most often, either no PCP or PCP not engaged because:

- Don't believe, don't want to get involved
- Don't understand, too complex
- Uncomfortable practicing outside standard medical practice
 - Put off by lack of diagnostics, FDA-approved treatments, research
- Punished by health plans for time spent, thinking outside the box
- May be easier to engage specialists than PCPs

Challenges in attracting clinicians to ME/CFS clinics

In addition to above:

- Practice too narrow, too "off-track"
- ME/CFS too complex/demanding
- Hard to provide competitive salary without increasing rates

These factors outweigh the selling point of ME/CFS being fascinating, cutting edge medicine

Barriers to Increasing # of Willing/Able Providers

Knowledge and attitudes

- **Clinician stigma and misinformation**
- **Lack of clinician knowledge**
- **Complexity of disease, lack of interest in managing chronic illness**
- **Perceived lack of treatment options**

Reimbursement

- **Reimbursement insufficient to cover time, tests, treatments**
- **ICD coding, insurance policies, etc.**

Lack of research

- **Lack of research and research funding, slow progress**
- **Lack of clinical treatment trials and evidence for treatment options**

Lack of institutional, med society support

- **Lack of support from institutions, peers, medical associations, etc.**
- **Lack of access to support services—e.g., case managers/social services**
- **Level/type of support needed for severely ill**

Impacting both # of PCPs and specialists as well as ME/CFS experts

Medical Education Initiatives Undertaken

Hands-on learning opportunities

- Some provide rotations, internships, etc. for pre-med through practicing docs
- Numbers are small
- Some go on to specialize in ME/CFS; Most do not

Materials for providers

- Primers, IOM material, ME/CFS Clinician Coalition website, etc.
- Lecture material, selected journal articles, online clinic videos
- "Most physicians not interested"

Other types of educational Initiatives

- CMEs
- Presentations at conferences, medical meetings, academic centers, etc.
- Develop consensus articles for clinical audience—but hard to get published
- Consults and list-serve discussions
- Case-based tele-mentoring (*formal program in planning*)

***These efforts barely scratch the surface of need...
...and only reach those already interested***

What is Needed to Mainstream ME/CFS

Proactive leadership, comprehensive awareness and education program

- Proactive leadership from federal agencies and medical societies
- Fully funded, comprehensive program to refute stigma/disinformation, and provide basic education and advanced learning opportunities
 - Including stipends to support the educators, hands-on learners

Fix reimbursement issues

- Especially for internists, family practice doctors, for complex diseases
- Reality based for time and complexity, not just "code" based

Healthcare incentives for complex, chronic cases

- Medical institutions, managed care groups, etc. must incentivize
- For the full spectrum of illness, including the severely ill

Diagnostics and treatments

- More clinical tools to treat and care for patients
- Requires research! Must make ME/CFS research funding a priority

Clinical care centers with team-based approach

- PCPs, clinical subspecialties, PTs, OTs, case mgrs., support services, etc.
- Centers with clinical care plus research and education

This is an Urgent Crisis

It is impossible to overestimate the significant lack of ME/CFS clinical care and its impact on people with ME/CFS

Now, the prevalence of ME/CFS could quickly double as the result of the long-term impact of COVID-19

Fixing this requires proactive leadership and a significant commitment from both you and key medical societies

Thank You