Public Comment
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Availability and cost are among the most common barriers to healthcare services.

Inability to access appropriate healthcare is common in this community. Patients often spend many months and in some cases over a year, on a waiting list to see a healthcare provider knowledgeable about ME. These healthcare providers are often quite some distance from the patient's home. So accessibility must include the distance traveled to get to the appointments, and the need for follow-up appointments.

Cost isn't limited to premiums, and co-pays (if the healthcare provider takes insurance). Because of the distances patients must travel, costs include travel, food and lodging. Additionally there are costs for treatments and tests (such as 2-day CPET) that aren't covered by insurance, as well as costs related to time off from work for those traveling with patients.

A disturbing trend associated with both cost and accessibility is the increasing numbers of concierge doctors (http://whartonmagazine.com/issues/spring-2012-2/concierge-medicine-the-doctor-is-always-in-if-you-pay-enough/) who charge an annual fee in addition to fees for office visits, etc.

Many patients are impoverished, or at best "getting by". Travel to appointments uses scarce physical and cognitive resources but also uses limited financial resources. So when it comes to concierge healthcare, very few patients can afford the average $1600 per person yearly fee to be part of a concierge healthcare practice.

Concierge practices limit membership and, in at least some cases, only invite certain patients from the existing patient roster.

I know siblings who had the same healthcare provider. When the practice "went concierge", one of the siblings received numerous solicitations to join. Little surprise that the one who *was* invited to join, was not nearly as sick as the sibling who was never invited to join, and who in fact received written reminders to find another healthcare provider.
Accessible healthcare for these siblings became even more limited because their healthcare provider became concierge only.

CFSAC has often talked about the need for Centers of Excellence (https://wayback.archive-it.org/3919/20140324192829/http://www.hhs.gov/advcomcfs/recommendations/cfsac-recs513.pdf) as well as the need for education of medical professionals and in fact has recently had a CFSAC Education Working Group.
(http://www.hhs.gov/advcomcfs/meetings/presentations/dr_sue_levine-jan27.pdf)

Accessibility to knowledgeable healthcare professionals is yet another reason we need Centers of Excellence for this illness. It is also why we need to greatly expand the ranks of appropriately educated medical professionals. I urge the CFSAC to consider how these can best be accomplished.