



MEMO

Date: August 5, 2021
To: External
From: Sick Cells

RE: July 2021 Policy Update

In July, we focused entirely on our community [Congressional Hearing Request](#). Read our updates below to learn more about our own initiative, as well as collaborative efforts with other organizations.

1. **Sick Cells met with 7 Congressional offices** and expects to meet with at least one more to discuss a potential FY22 Congressional hearing on the [2020 NASEM Report on SCD](#). This brings our total number of meetings with offices to over 50 for 2021. Offices targeted in our July outreach include:
 - a. Rep. Bill Foster
 - b. Rep. Danny Davis
 - c. Rep. Bobby Rush
 - d. Rep. Barbara Lee
 - e. Rep. G.K. Butterfield
 - f. Rep. Michael Burgess
 - g. Rep. Terri Sewell
 - h. Rep. Robin Kelly

Conversations with these offices have yielded a positive response to this initiative. Continuing discussions will focus on determining how to best work with other Members, agencies, and community-based organizations to maintain momentum on this report and its associated programs.

2. **Sick Cells attended ASH's quarterly policy meeting**
 - a. As a member organization of the American Society of Hematology's SCD Coalition, Sick Cells continues to build relationships and collaborate on policy issues.
3. **NORD announced a new [RDAC](#) in Louisiana**
 - a. Sick Cells was a signing organization on the RDAC request letters in Louisiana. *The council is currently recruiting members.* Contact RDAC@rarediseases.org if you are interested in getting involved.

See you in August!

Sick Cells 501 (C)(3) Nonprofit | www.sickcells.org
Mailing Address | 1042 Maple Ave STE 103 | Lisle, IL. 60532
DC Office | 1012 14th Street STE 500 | Washington D.C. 20005
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info@sickcells.org