



MEMO

Date: January 27, 2022
To: External
From: Sick Cells

RE: January 2022 Policy Memo

Welcome to 2022! After a much-needed break at the end of 2021, the staff at Sick Cells is back and ready to dive into the work we began last year and continue planning new initiatives to launch this year. Please read the following updates on our policy work so far.

1. **Sick Cells will host our annual Policy Forum** on March 22nd & 23rd
 - a. The Policy Forum is open to individuals enrolled in the [Sick Cells Ambassador Program](#)
 - b. For a full summary of the Policy Forum, please see [this special issue memo](#)

2. Sick Cells will continue to **participate in external policy workgroups**
 - a. [Leavitt Partners](#)
 - i. To discuss (1) access to new therapies, (2) data, and (2) care delivery & access
 - b. [EveryLife Foundation Community Congress](#)
 - i. To discuss (2) access to care, (2) P&T/DURB Advocacy

3. **Sick Cells signed three letters** in January
 - a. [HIV + Hepatitis Policy Institute](#) and the [Autoimmune Association](#)
 - i. Signed by 51 patient groups, to HHS Secretary Xavier Becerra
 - ii. Comments to the U.S. Department of Health and Human Services (HHS) on the *Notice of Benefits and Payment Parameters* (NBPP) for 2023 [proposed rule](#)
 - iii. **Read the letter [here](#)**
 - b. National Organization of Rare Disease's [Project RDAC](#)
 - i. Support for [Assembly Bill 744](#): Rare Disease Advisory Council in Wisconsin
 1. Signed by 13 organizations
 2. Establishes a Rare Disease Advisory Council in the state
 - ii. Support for [House Bill 458](#): Rare Disease Advisory Council
 1. Signed by 18 organizations
 2. Establishes a Rare Disease Advisory Council in the state

See you in February!

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