**Group Guide: Defining Advocate Roles**

We recommend that teams plan in advance which group member will talk about which issue in order to optimize your meetings. Depending on your group’s size, one person may take on multiple roles or two people may comment on the same issue.

Use phrases like ‘I’ll pass it to [Team Member]” to tee people up and keep the meeting moving smoothly.

***And always remember – your story/experience with psoriatic disease is the most important part of each meeting.*** The NPF team is here to help with your strategizing!

|  |  |  |
| --- | --- | --- |
| **Role** | **Responsibilities** | **Notes** |
| **Meeting moderator** | * Keep track of who has joined at the start of each meeting. (Virtual) * Kick off the meeting by introducing the group and asking the staffer if they are familiar with psoriatic disease. * Keep the conversation moving between group members throughout the call. | Ideally, the moderator will be a constituent. If it’s easier, the moderator can remain the same for all meetings within a single state.  For member level meetings, the constituent should be the moderator or start off the meeting. |
| **Constituent(s)** | * Identify yourself as a constituent during introductions and state where you are from. * Close the meeting by thanking the member of Congress/their staff and stating follow up items. | The constituent(s) will change each meeting. If there are multiple constituents, decide who will go first for each meeting. |
| **Ask 1: Psoriatic disease appropriations** | * Talk about your experience in getting diagnosed and finding the right treatment. * Explain why it is important to continue this work to improve diagnoses and public health interventions. | Coordinate among group members to identify who can best speak to this issue and share their story. |
| **Ask 2: The Safe Step Act** | * Talk about how step therapy impacts people with psoriatic disease. * Explain why it’s important to support federal step therapy protections by cosponsoring the Safe Step Act. | Coordinate among group members to identify who can best speak to this issue and share their story. |
| **Ask 3: HR 830, The HELP Copays Act** | * Talk about the importance of copay assistance to you/the psoriatic disease community * Explain how ensuring all copay assistance counts toward the deductible would improve the health and quality of life of those living with psoriatic disease. | Coordinate among group members to identify who can best speak to this issue and share their story. |

Sample Script – 2023 Capitol Hill Day Meetings

|  |  |
| --- | --- |
| Intro  to  group | **Moderator:** Thank you for taking the time to meet with us today.  My name is \_\_\_\_\_\_\_\_\_\_. I’m here with [number] constituents and other National Psoriasis Foundation advocates on behalf of the over 8 million Americans who live with psoriasis/psoriatic arthritis. We hope to discuss:   * Appropriations for psoriatic disease at CDC * The Safe Step Act, and * HR 830, The HELP Copays Act   Let’s start with a round of introductions. [Call on first constituent], I’ll pass it you first. *(If moderator is first constituent, just go into your introduction below)*  [**Constituent**] My name is \_\_\_\_ and I am a constituent from \_\_\_\_\_\_\_\_\_\_\_.  *[Briefly state your connection with psoriatic disease (under 1 minute)]*  ***Moderator should call on the other group members.***  [**Other group members**] My name is \_\_\_\_ and I’m from \_\_\_\_. [Briefly state your connection with psoriatic disease (under 1 minute)]. |
| **Intro to psoriatic disease** | **Moderator:** Are you familiar with psoriatic disease?  *Wait for response from staff/legislator*  As you know/psoriatic disease includes psoriasis and psoriatic arthritis. These are chronic, immune-mediated diseases that affect about 1 in 30 adults in the US. People with psoriatic disease are also at higher risk of co-occurring conditions, including diabetes, cardiovascular disease and depression. Despite advances in treatment, many are diagnosed late, and many have not achieved remission. |
| **The asks** | **Moderator:** I’ll hand it over to [**Ask 1 person**] to talk about our first issue.   1. **Support appropriations for CDC’s work on psoriatic disease.**   **Ask 1 person:** As we discussed in our intro, psoriatic disease represents a significant public health burden.  [Share your story about getting diagnosed or finding appropriate treatment (under 1 minute)]  The CDC Chronic Disease Education and Awareness Program is supporting efforts to improve our understanding of the prevalence and impact of psoriatic disease. It is also working to improve diagnosis times.  We need continued support from CDC to maintain this progress. That is why we are asking you to include in your fiscal year 2024 appropriations request:   * $6 million for the CDC Chronic Disease Education and Awareness Program * Report language encouraging CDC to continue its work on psoriatic disease.   **In the House:** Will you include this funding and report language in your FY24 appropriations request? In addition, please join a bipartisan sign on letter led by Reps. Joyce and Wasserman Schultz to support these asks.  **In the Senate:** Will you include this funding and report language in your FY24 appropriations request?  **2. Support Federal Step Therapy Reform**  *Note: Has this member previously or currently cosponsored the Safe Step Act?*   * *If yes, thank them for their support. For previous supporters, let them know and follow the script below.* * *If not, follow the script below by asking if they are familiar with step therapy.*   **Ask 2 person:** Insurance-mandated step therapy delays access to treatment for people with psoriasis and psoriatic arthritis. Are you familiar with step therapy?  *Wait for response from staff/legislator*  So you know that/Step therapy is when a health plan requires patients to try – and fail – one or more medications before the plan will cover the drug originally selected by the patient and their provider. Step therapy can delay access to critical treatments, which can result in severe or irreversible disease progression like permanent joint damage for people with psoriatic arthritis.  For me, step therapy means [Share your story about how step therapy has or would impact you, or how the exceptions in this bill would have made your treatment journey easier (under 1 minute)]  **Ask person 2 or (optional) additional speaker:** The Safe Step Act would ensure that patients and providers can access a medically reasonable and expedient step therapy exceptions process. This bill does not ban step therapy but puts guardrails in place to ensure patient safety.  *(Check if your state has passed step therapy. If so, mention it below.)*  36 states, including [state], have passed similar step therapy reform laws. However, federal step therapy reform is needed to expand those protections to Americans with employer plans.  Will the Senator/Representative cosponsor the Safe Step Act?  [wait for staffer to reply]  Thank you. I will hand it over to [**Ask 3 person**] to talk about our next ask:  **3. Support the HELP Copays Act**  *Note: Has this member previously or currently cosponsored the Help Copays Act?*   * *If yes, thank them for their support. For previous supporters, let them know and follow the script below.* * *If not, follow the script below by asking if they are familiar with copay assistance programs.*   **Ask 3 person:** Patients with complex and chronic illnesses often rely on copay assistance programs to afford specialty medications essential to their health. Are you familiar with copay accumulators?  [wait for staffer to reply]  Copay assistance helps many in our community afford their treatments. Over the last few years, insurers have been implementing copay accumulator adjustment programs in which they accept copay assistance, but do not count it towards the individual's annual deductible or out-of-pocket maximum. As deductibles and out of pocket maximums rise, copay accumulators make it impossible for patients to afford their medications.  For me, copay assistance means [Share your story on how copay assistance and copay accumulators have or would impact you or a loved one (under 1 minute)]  The HELP Copays Act would ensure that all copay assistance is counted towards the plan user’s cost sharing requirements.  **In the House**: Will you cosponsor HR 830, the HELP Copays Act?  **In the Senate**: Would you consider introducing companion legislation in the Senate? |
| **Meeting wrap up** | **Constituent (if more than one, designate ahead of time**): Thank you for speaking with us about the issues affecting our community. As discussed, we hope your boss will:   * Include $6 million for the CDEA, and report language on psoriatic disease, in your FY24 appropriations request * Cosponsor the Safe Step Act, and * Cosponsor/(For Senate:Introduce) HR 830, the HELP Copays Act   Pleaselet us know if you have any questions and we will make sure to follow-up with you in the next week.  Feel free to contact me with any questions. I can also put you in touch with National Psoriasis Foundation staff who can provide any additional details on these issues. |