Advocacy: Rare Disease Week Informational Session Meeting Minutes
January 7, 2025
1:00PM Pacific/4:00 PM Eastern

Quick Recap

The group discussed plans and logistics for various upcoming advocacy events, including a legislative conference, NIH's Rare Disease Day event, and Rare Disease Week, with participants coordinating travel arrangements, hotel accommodations, and networking opportunities. They explored strategies for engaging with policymakers, preparing materials for these events, and emphasized the importance of building relationships with legislative staff and utilizing social media for community empowerment. The team also discussed advocacy priorities, including pheo/para research funding, and coordinated plans for creating promotional materials and organizing team activities during the week-long event.

Meeting Minutes

Event Planning and Community Building

There is limited time (max of 10 minutes for the whole group, not individual time) for interactions with representatives. It is so important to attend despite the constraints though. The event is incredible in fostering a sense of community. Based off of past experience, we highly encourage participants to wear comfortable shoes.

Engaging Congressional Staff Strategies

The location of meetings (hallway, office, or conference room) with legislative staff depends on the status and availability of the elected official and their staff. It’s important to engage with staff members, particularly those with medical expertise, as they often make key decisions.

Legislative Conference Registration and Preparation

On the registration page, you will be asked if you are interested in being a team coordinator. The role of a team coordinator involves organizing speaking orders for office visits. We encourage you to volunteer, especially if you have prior experience or organizational skills. There are also two preparatory sessions offered by Every Life Foundation: an information session and a session for preparing personal stories, which are highly recommended for first-time participants.

Advocacy Event Logistics Planning

The group discussed logistics, including a welcome reception on Tuesday evening that features appetizers and a viewing of rare disease videos. The group also noted that the registration process has evolved over the years, with more detailed information provided in previous years about pre-event activities.

NIH Rare Disease Day Planning
The group discussed plans for attending NIH's Rare Disease Day event on Friday. Several participants, though, expressed uncertainty about attending due to travel logistics and mixed reviews about the event's format. The group also learned that the event at NIH would be video streamed for those unable to attend in person.

Washington D.C. Trip Accommodations
The group discussed hotel accommodations for an upcoming trip to Washington D.C., with one member sharing their list of nearby accommodations.

Pheo Para Advocacy Strategy Meeting
The group discussed strategies for advocating for pheo/para research funding and visibility, including reviewing NORD's legislative priorities and aligning pheo/para talking points with their messaging.

Q&A

- General overview of the weekend itinerary & costs associated with attending?
    - Please see above for the general itinerary
    - No fee to attend; purely travel
    - Deadline has passed, but there is a travel scholarship that’s offered each year
- Can we get insurance companies to support annual screening for rare diseases with genetic markers and family history? (question submitted by a registrant)
    - Insurance companies won’t be at the event, but pharmaceutical companies will be present
- Where is a good place to stay?
    - Crystal City is another place to consider in terms of affordable accommodations.

Reminder: Registration for RDW opens today, January 7th!