Thank you for your interest in the 2020 Advocacy Conference! For those of you who are first-time advocates and who are wondering “what is this conference all about,” this set of Frequently Asked Questions (FAQ) is designed to answer many of the questions we often hear from those interested in learning more about the conference.

Q: What are the scheduled activities during the Advocacy Conference?

A: The conference takes place over the course of 3 days (Sunday through Tuesday). On Sunday we hold an Advocate training at the hotel from 3pm-7pm where we will go over the “request or ask” we are making to Congress and get everyone well prepared for hill meetings. You will be grouped with other Advocates from your home state. Your meetings on the hill will take place on Monday and Tuesday.

Q: How are meetings with our Senate and House members scheduled?

A: Meetings will be scheduled for you by PPMD. We use a company called Soapbox Consulting who handle all the scheduling. Meetings are scheduled ahead of time between you and the appropriate health policy staffers who work for your two Senators and one Representative. If schedules permit, your Senators and/or House Member may participate in your meeting or at least stop in for a minute or two to shake your hand. Meetings are scheduled between the hours of 9am – 5pm Monday and Tuesday so please let us know if travel conflicts with these times (particularly when you fly home). Soapbox will email you a schedule for you to review a few days prior to the conference.

Q: How many meetings will I have?

A: You are guaranteed 3 meetings. 2 with your Senate offices and 1 with your House member. You are normally grouped with other Advocates from your state so your schedule will most likely include meetings with their house members as well, meaning, your schedule will most likely contain more than the guaranteed 3 meetings.

Q: Are any meals covered during the conference?

A: We provide dinner on Sunday night and breakfast on Monday morning for all Advocates.
Q: Who will I be traveling to meetings with, and how will I know where to go?

A: If you’ve never been to Washington before, don’t be afraid as you will be traveling in groups that will include experienced advocates and/or government relations advisors from PPMD. Each Advocate will receive a personalized schedule with the times and locations of each meeting, as well as the staff members with whom you will be meeting. We will also provide you with maps and show you the lay of the land. All of your meetings will be taking place in office buildings that are part of the Capitol complex.

Q: Advocacy feels out of my comfort zone and expertise. Am I expected to know a lot about legislation and public policy?

A: Not at all. Your main job while on the hill is to tell your personal story, educate them about Duchenne, and explain how Duchenne impacts your family. We will provide you with a folder that you can leave behind with the office that has the details of our request. We also give you talking points so you can make the request in your meeting. But overall, you are not expected to be an expert in policy and legislation, your most important goal is to tell your personal story. We will have seasoned Advocates and PPMD staff who will accompany Advocates on meetings.

Q: What are we asking Congress to do?

A: We are asking members of Congress to sign a letter that supports funding of the federal agencies that impact Duchenne the most— including The National Institutes of Health (NIH), the Center for Disease Control (CDC), and the Food and Drug Administration (FDA). Congress provides funding for these agencies along with “guidance” of how to spend the tax payer dollars. The letter we have members sign requests that the funding “guidance” includes our Duchenne specific language. We will explain how this works in more detail during Advocate training on Sunday.

Q: What is the dress code?

A: Dress is normally business casual on the hill. But be sure to wear comfortable shoes and check the DC weather before you leave!

Q: What should I/can I bring?

A: We encourage you to bring pictures as a leave behind with your packet folder. It is important they put a face to Duchenne and Becker.

Q: What is the cost of the Advocacy Conference?

A: There is no conference fee to register. The cost of the conference comes down to travel to DC and cost of the hotel. The hotel block information can be found on the main advocacy conference registration page.

We have some Advocates who share hotel rooms in order to split the cost. Please let Ryan Fischer (ryan@parentprojectmd.org) know if you are interested in being matched with someone. If you find a hotel that is cheaper nearby you are more than welcome to stay wherever you’d like. We understand participation in this conference is not without costs.