



PCHA Advocacy Conference

Advocate Packet



Conquering CHD in Washington D.C.

March 2-3, 2020

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Introduction

Welcome to PCHA's 2020 Advocacy Conference!

Your story matters and sharing your journey with your lawmakers is an important part of our ongoing advocacy activities. Our hope is that you have a wonderful experience!

This packet contains important information that will be helpful as you plan your trip to Washington D.C. **Please look through all of this information carefully.** You will find information about what to wear and preparing something to leave with your lawmakers. We've even got a sneak peek at what we will be talking about on Capitol Hill, with additional details to follow as we get closer to the conference.

After reading this packet, if you have any questions or concerns, please email advocacy@conqueringchd.org.

Together, we are Conquering CHD!

Agenda

Monday, March 2nd	
7:30 am – 8:30 am	Registration / Breakfast / Meet and Greet
7:30 am – 8:30 am	Coffee for Those Who Have Lost Loved Ones
8:30 am – 8:45 am	Welcome and Introductions <ul style="list-style-type: none"> • David Kasnic, PCHA Executive Director
8:45 am – 9:30 am	Keynote presentation <ul style="list-style-type: none"> • Callie Chiroff D.N.P, APNP
9:30 am – 10:15 am	Our Impact <ul style="list-style-type: none"> • A little bit of history / the impact we have had • Our ask (background and emphasis on one liners)
10:15 am – 10:30 am	Break
10:30 am – 11:30 am	Wisdom from across the table <ul style="list-style-type: none"> • Legislative Staff Panel <ul style="list-style-type: none"> - Shayne Woods, Senior Policy Advisor – Congressman Gus Bilirakis (R - FL) - Max Kanner, Health Policy Advisor – Senator Richard Durbin (D – IL) - Jaymi D. Light, Legislative Assistant – Senator Todd Young (R – IN)
11:30 am – 12:30 pm	Lunch and social time
12:30 pm – 1:30 pm	Your Voice Matters <ul style="list-style-type: none"> • Brief how to tell your story overview • Advocate Panel – sharing experiences <ul style="list-style-type: none"> Adult Patient: Eva Edinger Parent: Jess Chenevert Teen: Trinity Higgins Youth: Lucas Iguina Bereaved: Trey Flynn
1:30 pm 1:45 pm	Break

1:45 pm - 3:00 pm	In depth look at the issue: <ul style="list-style-type: none"> Panel of experts • CDC: Jill Glidewell • NIH: Kristin Burns • Disparities: Heather Langlois • Transparency: Ram Subramanyan, MD (10 min each with 30 minute discussion)
3:00 pm - 3:15 pm	Break
3:15 pm - 3:45 pm	Ready, Set, Teamwork - Preparing for our meetings tomorrow <ul style="list-style-type: none"> • Making of An Effective Team
3:45 pm - 5:00 pm	Schedules and Practice <ul style="list-style-type: none"> • Soap Box Distributes Schedules • Coordinate and Practice as a State
5:00 pm - 5:30 pm	Break
5:30 pm - 9:00 pm	Dinner; Program begins at 6:15

Tuesday, March 3rd	
7:00 am - 8:00 am	Breakfast
8:00 am - 9:00 am	Welcome and Advocacy Day Kickoff!
9:30 am - 4:30 pm	Hill Visits in Teams <i>Note: The Hospitality Room is available after 12pm</i> <i>Lunch will be on your own</i>

Accommodations & Travel Information

HOTEL

InterContinental Washington D.C. - The Wharf
801 Wharf Street SW, Washington, District of Columbia, 20024
1-833-249-1029

Your registration does not include travel accommodations. We encourage you to book your travel and make hotel reservations early, as options are limited.

We have arranged a special group rate of \$349/night for Advocacy Conference attendees. The Group Code is PCHA Advocacy Conference.

The deadline to reserve at this rate is January 29.

Each individual guest must make their own hotel reservations by:

- Booking online [HERE](#) (Group code is ZX5)
- Calling the hotel directly at 1-833-249-1029 by 1/29/2020. Guests must identify themselves as members of the PCHA Advocacy Conference.

All reservations must be accompanied by a first-night room deposit or guaranteed with a major credit card.

For those who are local or driving in, valet parking is available for a daily rate of \$58.00 per night, including in and out privileges. Rates are subject to change. Oversized and bus parking is located at Union Station (50 Massachusetts Ave NE, Washington, DC 20002).

AIRPORT

Ronald Reagan Washington National Airport (DCA), Arlington, VA 22202
<https://www.flyreagan.com/dca/reagan-national-airport>

Located just 3.5 miles east of The InterContinental, the Ronald Reagan Washington National Airport site is rich in historical significance dating back to colonial days, offering a variety of services, amenities and facilities available to make your trip pleasurable, comfortable, and efficient. Complimentary Wi-Fi and charging stations, a USO Lounge, multiple nursing rooms, and much more are available.

Through the airport, visitors can experience diverse regional, national and international rotating exhibits, dynamic live performances and new and innovative public art displays that celebrate the stately beauty, spirit and great creativity of the National Capital Region. As part of the

performing arts program, the Airport Authority brings musicians, singers, dancers and other artists to Washington's airports to provide entertainment for passengers to enjoy throughout the year. The Gallery Walk is located in Historic Terminal A between the Historic Lobby and the present-day ticketing lobby. The gallery includes case displays and wall display areas for two and three-dimensional works by artists from all over the local area.

There are ten on-premise auto rental agencies, plus plenty of shuttle bus services that operate 24 hours a day, and taxis available to help you get from the airport to wherever you need to go. The Washington, DC Metrorail system has an elevated Metrorail station connected to the concourse level of Terminals B and C at Reagan National Airport. The Metrorail system provides easy and affordable access to locations throughout Washington, Virginia and Maryland.

MEALS

Your conference registration covers the following meals: Breakfast, Lunch and Dinner on Monday, as well as a light breakfast on Tuesday. You will be on your own for Lunch on Tuesday with many restaurants and cafes available within the Senate and House office buildings for your convenience. There will be an assortment of light snacks for you to take with you to Capitol Hill.

TRANSPORTATION TO CAPITOL HILL ON TUESDAY

On Tuesday, you will be traveling from the Intercontinental Hotel to Capitol Hill to meet with your legislators. It is approximately 1.5 miles and a 30 to 35-minute walk for those who are up for it. We will be offering an \$8 Metro Card for those who would prefer to ride the Metro. It is a 10-minute walk to the nearest Metro Station (L'Enfant Plaza) and no train changes are required to get to House Office Buildings (Capitol South Station). For information about navigating the metro system check out this [DC Guide to the Metro](#). Any other forms of transportation (taxi or shared ride service) are at your own expense.

If you are departing on Tuesday, you are welcome to check your luggage with the Hotel Concierge. It may be a burden to lug your things around to your meetings on the Hill.

Top 10 Tips to Be Prepared

- 1) **Know “the ask”.** It is important that you stay focused on the key issues we will be covering on this day. We know there are so many more things to talk about, but when we all share the same message, it has a much bigger impact. We will provide you with all the information you need as we get closer to the event. We will also review the messaging in depth during the conference.

SNEAK PEEK:

- a) We will be asking for increased funding for CHD research and data collection. It is important that we continue to ask for money to be included in the budget each year.
 - b) We will also be talking about hospital quality and safety and how patients and families get information to help them make decisions.
- 2) **Practice telling your story.** Your story is what moves your lawmakers into action. But you only have a few minutes to get your point across. So, you need to practice being brief. It can be difficult, we know! We will cover this during the conference as well.

Here’s a few things to think about

- Be clear - use simple words rather than medical terms. It is likely that the people you meet are not familiar with congenital heart disease at all.
 - Be accurate - your story as it really happened is powerful.
 - Be emotional - it’s ok to let your feelings show. In fact, it can be very persuasive. No need to focus on the statistics, we will provide that in a folder to leave with them.
 - Be brief - plan on 2-3 minutes to tell your story and make an impact. If you are allowed more time you can share more but start with a short version.
 - Be polite - the most important part of advocacy is building relationships with your legislators and their staff. Even if you don’t agree on things, it is important to focus on the common ground, and always be grateful.
- 3) **Know the basics about your Senators and Representatives.** We will schedule your meetings with your legislators based on the address you provided us when you registered. However, we encourage you to learn a few things that might help you better understand where they are coming from. You can find the names of your lawmakers and their websites here: www.senate.gov and www.house.gov.
 - 4) **If you already know a Member of Congress or a staff person, let us know.** It helps when we are scheduling visits if we can acknowledge that personal connection you’ve already worked so hard to make. If this person is not *your* representative, we can still try to arrange an opportunity to stop by the office.

- 5) **Understand that Congressional staff are important too.** It is possible that your legislator may not be able to attend your meeting in person. Instead, you will meet with his or her staff. The role of the staff members is to become the issue experts and help inform the views of the legislators. Building strong positive relationships with the staff is key.
- 6) **Create something to leave with the staff member.** It is important to provide the office with your contact information to make follow-up easier. This can be as simple as a business card, but you can also create a more memorable personalized piece to make an even bigger impact. Examples include a valentine, or photo card similar to a Holiday Card you may send to friends.
- 7) **Dress for Success.** When building relationships, first impressions do matter. Here's a few things to consider:
- Dress for the conference is business casual. You may have the opportunity to be photographed with members of Congress or their staff joining us for the conference.
 - Dress for the dinner is casual. Some people change and others wear what they've had on all day.
 - Dress on Tuesday for Hill meetings is professional attire. This includes suits, dress pants, jackets, ties, dresses, skirts and blouses. No jeans, please.
 - Dress for the weather, particularly on Tuesday. You will likely have to spend some time outside walking between office buildings.
 - Wear comfortable shoes. Trust us. If you really want to wear heels, we strongly suggest that you bring a second pair of comfortable flats to slip on between meetings. Even those who have done this for years report that their feet still hurt at the end of the day.
- 8) **Plan carefully if bringing a young child.** It is important that children learn to advocate for themselves, however, this can be a challenging environment, especially for young children. We will offer youth programming for older children during the afternoon of the conference so they can learn age-appropriate ways to share their story.
- A few tricks can make the experience better for everyone:
- Bring another caregiver. The days can be long and boring. It may be helpful to have a second person to tag-team with in entertaining a young one.
 - Consider timing of naps and rest breaks. Meetings with legislative offices require extra-good behavior. It is ok if your child skips a meeting or two if they are not up for it.
 - Pack extra food. Kids (and adults, for that matter) get hungry at different times. Since everyone is out of their element, having extra food that your child is familiar with can do wonders!
 - Consider bringing a stroller. There is a lot of walking.

- Talk about CHD before you come. Some of the things that people talk about during the meeting may be upsetting to children who do not understand the complications of CHD.
- 9) **Get Excited!** If this is your first time, you may be a little nervous. That is totally normal. But, those who have come before will reassure you that this is where you get to meet new friends, celebrate old friends, learn more about CHD, and share your story in a way that really matters. An experience you will never forget!
- 10) **Ask Questions.** Don't hesitate to email advocacy@conqueringchd.org with any questions you may have. We are happy to help make sure you have the best experience possible.
- 11) **Wear comfortable Shoes.** Really. We aren't kidding.

Once You Get to D.C.

TRAINING

During the conference on the first day, we will provide you with loads of information about congenital heart disease, what we will be talking about during the legislative visits and how to tell your story. You will hear first-hand from experienced advocates, medical experts, representatives from federal agencies, legislative staff, and Members of Congress.

You will also meet the other advocates who will join you in your legislative visits. You will have the chance to practice sharing your story together and talk through what a meeting is like.

MEETING SCHEDULES

We will schedule all legislative meetings for you. As we mentioned earlier, please let us know if you already have a relationship with someone who works in the House or Senate.

You will receive your schedules at the end of the day on Monday. This will give you time to look at the day ahead. You can identify the locations of the offices you will be visiting, and begin to plan what time you need to leave in the morning, when you will be done at the end of the day and think about timing between visits. We will provide a map of the Capitol Complex to help you plan your travel routes.

There are security checkpoints with metal detectors and x-ray machines when you enter the Senate Complex and the House Complex. You may need extra time if you have an implanted device. Once inside a complex you will be able to travel indoors between buildings. However, the building layouts can be confusing so be sure to allow enough time between visits to find your way.

It is extremely important to be on time.

THE MEETING

Your training during the conference will include a review of key things to remember for a great meeting. You will be working with other advocates as a team and we will include time to practice things like introductions, covering the key talking points, and sharing your story.

We want to remind you that it is very important to stay on topic. Some small talk is acceptable but be sure to bring it back to the key issues we are trying to communicate. It is also easy to get lost in telling your story - keep it brief and tie it in to the key issues. **DO NOT** discuss other political topics outside of our key issues as it greatly reduces the impact of your meeting. As a team, you can hold each other accountable.

The important thing to remember is that these meetings are about building relationships. By sharing your story, you can move your Members of Congress to take action on the key issues.

THE ALL-IMPORTANT FOLLOW-UP

Advocacy doesn't end when you leave the meeting. In fact, you've only just begun! We will ask you to share your experience through an online feedback form. Let us know if your Member agreed to take action, if there were any questions that need answers, or any other urgent follow-up we can help with.

Continue the conversation with your lawmakers and their staff. You will likely receive the business cards of the staff members you meet with. This is your Golden Ticket. We encourage you to send a thank you email as soon as possible after your visits. You can also follow-up throughout the year providing them updates on key issues, pass along key articles about CHD in the news, or simply fun experiences you are having Conquering CHD.

Congratulations for getting this far - if you have any questions, at this point, please email advocacy@conqueringchd.org.

Continue reading for a handy resource to help you create a personal leave-behind.

Creating a Personalized Leave-Behind

It is important to leave something behind when visiting your legislators to help them remember your visit, and to provide them with your name and contact information should they have any questions.

We will provide you with folders for each meeting that will include fact sheets about our issues and our ask. But it is equally important to leave something that will help them remember *you*.

Often times we recommend a business card. But former hill staffer and CHD advocate Meredith Atkinson advises something a little more personal:

“Hill staffers are inundated daily with endless amounts of paper and email full of information. Many of the staffers we visit are young, straight out of college, and don't have personal experience with kids, let alone kids with heart disease. Visuals are always helpful, and I want them to see what a kid having heart surgery looks like—but, I also don't want to scare them. Our family makes two-sided cards, one with a sweet photo and short message on the front and a more graphic photo from surgeries and details on the back. We've changed the cards and pictures up over our years, but they are more or less the same. “

MAKING IT PERSONAL

Some advocates make their cards by hand, using photographs and craft supplies. Others use photo greeting card templates and have them printed. Whichever route you choose, keep the messaging simple:

- o Limit it to one statistic – we suggest using that CHD is the most common category of birth defects
- o Include our current issue(s)

Make enough. You will need to have at least three cards, one for each of your members of Congress. However, we suggest creating as many as 10-15 to distribute to other folks you may meet along the way.