



# DRAFT Conference Agenda for 2025

## Friday Afternoon, April 4th

Time	Session	Room (subject to change)
1:00 PM - 7:00 PM	Registration, AID help desk, Store	Lighthouse A
2:00 PM - 2:30 PM	Ice Breaker and New Member Welcome	Lighthouse B & C
2:30 PM - 3:30 PM	Survey Says	Lighthouse B & C
3:30 PM - 4:30 PM	Creating Inclusive Environments in healthcare & research - Panel	Lighthouse B & C
4:30 PM - 5:30 PM	Emergency & Clinical Trial Preparedness	Lighthouse B & C
5:30 PM - 6:30 PM	'TED Talks' HPS Style	Lighthouse B & C
7:00 PM - 8:00 PM	Dinner	Grand Ballroom
8:00 PM - 10:00 PM	Year in Review	Grand Ballroom
7:30 PM - 10:00 PM	Dance Party & Bingo (kids only)	Adelphi & Molloy
10:00 PM - 11:00 PM	Let's head to the bar!!!	Hotel Bar

# Saturday, April 5th

Time	Session	Room (subject to change)
7:30 AM - 8:30 AM	<b>Continental Breakfast</b>	Grand Ballroom
8:30 AM - 9:00 AM	<b>Welcome</b>	Grand Ballroom
8:00 AM - 4:00 PM	<b>Registration, AID help desk, Store</b>	Lighthouse A
9:00 AM - 11:00 AM	<b>Family Album</b>	Grand Ballroom
11:00 AM - 12:00 PM	<b>Breakout Groups</b> <ul style="list-style-type: none"> <li>● Adults</li> <li>● Parents</li> <li>● Partners &amp; Other Supporters</li> </ul>	Forum 3 Lighthouse C Forum 5
12:00 PM - 1:00 PM	<b>LUNCH with Breakout Groups</b> - in Grand Ballroom and Lighthouse C	
1:00 PM - 4:00 PM	<b>Registration, AID help desk, Store</b>	Lighthouse A
1:00 PM - 2:00 PM	<b>Breakout Session #1</b> <ul style="list-style-type: none"> <li>● The Brotherhood</li> <li>● Content Clubhouse</li> <li>● Whitehouse Advocacy Kickoff</li> <li>● META Glasses &amp; other assistive devices presentation</li> </ul>	Forum 5 Forum 1 Forum 6 Forum 2
2:00 PM - 3:00 PM	<b>Breakout Session #2</b> <ul style="list-style-type: none"> <li>● Current Assistive Technology</li> <li>● HPS 101*</li> <li>● Pulmonary Wellness</li> <li>● META Glasses &amp; other assistive devices up close look</li> </ul>	Forum 1 Forum 3 Forum 5 Forum 2
3:00 PM - 4:00 PM	<b>Breakout Session #3</b> <ul style="list-style-type: none"> <li>● Panel of Professional Adults with HPS</li> <li>● Fundraising Workshop</li> <li>● HPS Subtypes discussion group (excluding 1,2 &amp; 4)</li> <li>● Social Life with HPS</li> </ul>	Forum 1 Forum 2 Forum 5 Forum 3
4:00 PM - 5:00 PM	<b>Breakout Session #4</b> <ul style="list-style-type: none"> <li>● OBGYN Office Hours with Dr. Merideth *</li> <li>● "GI" Wish I Felt Better</li> <li>● Mental Health &amp; Sensory Disabilities</li> <li>● Paint Party</li> <li>● Content Clubhouse</li> </ul>	Forum 5 Forum 2 Forum 3 Lighthouse C Forum 1
7:00 PM - 11:00 PM	<b>Celebration Dinner (with cash bar) and Group Picture</b>	

# Sunday, April 6th

Time	Session	Room
8:00 AM - 8:30 AM	<b>Sunrise Session</b>	Lighthouse C
8:30 AM - 9:30 AM	<b>Continental Breakfast</b>	Grand Ballroom
9:30 AM - 10:00 AM	<b>Seeing the Inside of Research</b>	Grand Ballroom
10:00 AM - 10:30 AM	<b>HPS Awareness Celebration/6 minute walk</b>	Grand Ballroom
10:30 AM -11:15 AM	<b>HPS Overview*</b> <ul style="list-style-type: none"> <li>• Dr. William Gahl, NHGRI, NIH</li> </ul>	Grand Ballroom
11:15 AM - 11:45 PM	<b>HPS Pulmonary Health</b> <ul style="list-style-type: none"> <li>• Dr. Jesse Roman, Thomas Jefferson University Hospital, PA</li> </ul>	Grand Ballroom
11:45 AM - 12:30 PM	<b>Inflammatory Bowel Disease of HPS</b> <ul style="list-style-type: none"> <li>• Dr. Louis Cohen, Mount Sinai, NY</li> </ul>	Grand Ballroom
12:30 PM - 1:15 PM	<b>LUNCH</b>	Grand Ballroom
1:15 PM - 1:45 PM	<b>HPS Kidney Report*</b> <ul style="list-style-type: none"> <li>• Dr. Wendy Introne, NHGRI, NIH</li> </ul>	Grand Ballroom
1:45 PM - 2:15 PM	<b>Summation of the Meeting of the Minds</b> <ul style="list-style-type: none"> <li>• Dr. Samuel Seward, Chair of the HPS Network Scientific Advisory Board</li> </ul>	Grand Ballroom
2:15 PM - 2:45 PM	<b>Gene Therapy*</b> <ul style="list-style-type: none"> <li>• Dr. Gustavo Nieto-Alamilla, NIH</li> </ul>	Grand Ballroom
2:45 PM - 3:30 PM	<b>How do we stop bleeding?</b> <ul style="list-style-type: none"> <li>• Donna Appell, RN, Executive Director of HPS Network</li> </ul>	Grand Ballroom
3:30 PM - 4:15 PM	<b>HPS Standard of Care</b> <ul style="list-style-type: none"> <li>• Dr. Samuel Seward, Chair of the HPS Network Scientific Advisory Board</li> </ul>	Grand Ballroom
4:15 PM - 4:30 PM	<b>Closing</b> <ul style="list-style-type: none"> <li>• Donna Appell, RN, Executive Director of HPS Network</li> </ul>	Grand Ballroom

\*these sessions will be presented live via ZOOM