



DRAFT Conference Agenda for 2025

Friday Afternoon, April 4th

Time	Session	Room (subject to change)
1:00 PM - 5:00 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	'TED Talks' HPS Style	Lighthouse B & C
5:30 PM - 6:30 PM	Emergency Preparedness	Lighthouse B & C
7:00 PM - 8:00 PM	Dinner	Ballroom
8:00 PM - 10:00 PM	Year in Review	Ballroom
8:00 PM - 10:00 PM	Dance Party & Bingo (kids only)	Adelphi
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	Continental Breakfast	Ballroom
8:30 AM - 9:00 AM	Welcome	Ballroom
8:00 AM - 1:00 PM	Registration, AID help desk, Store	Lighthouse A
9:00 AM - 11:00 AM	Family Album	Ballroom
11:00 AM - 12:00 PM	Breakout Groups <ul style="list-style-type: none"> ● Adults ● Parents ● Partners & Other Supporters ● LGBTQIA+ 	Forum 3 Lighthouse C Forum 1 Forum 5
12:00 PM - 1:00 PM	LUNCH with Breakout Groups	in Ballroom and Lighthouse C
1:00 PM - 4:00 PM	Registration, AID help desk, Store	Lighthouse A
1:00 PM - 2:00 PM	Breakout Session #1 <ul style="list-style-type: none"> ● The Brotherhood ● Pulmonary Wellness ● META Glasses & other technologies 	Forum 5 Forum 3 Forum 2
2:00 PM - 3:00 PM	Breakout Session #2 <ul style="list-style-type: none"> ● Current Assistive Technology ● HPS 101 ● HPS Subtypes discussion group (excluding 1,2 & 4) ● META Glasses & other technologies 	Forum 3 Forum 1 Forum 5 Forum 2
3:00 PM - 4:00 PM	Breakout Session #3 <ul style="list-style-type: none"> ● Panel of Professional Adults with HPS ● Fundraising Workshop ● Social Life with HPS 	Forum 1 Forum 2 Forum 3
4:00 PM - 5:00 PM	Breakout Session #4 <ul style="list-style-type: none"> ● OBGYN Office Hours with Dr. Merideth ● “GI” Wish I Felt Better ● Mental Health & Sensory Disabilities ● Paint Party (sign up required) 	Forum 5 Forum 1 Forum 3 Lighthouse C
7:00 PM - 11:00 PM	Celebration Dinner (with cash bar) and Group Picture	Ballroom

Sunday, April 6th

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