



2025 Family Conference Agenda

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	Continental Breakfast	Grand Ballroom
8:30 AM - 9:00 AM	Welcome	Grand Ballroom
8:00 AM - 4:00 PM	Registration, AID help desk, Store	Lighthouse A
9:00 AM - 11:00 AM	Family Album	Grand Ballroom
11:00 AM - 12:00 PM	Breakout Groups <ul style="list-style-type: none"> ● Adults ● Parents ● Partners & Other Supporters 	Forum 3 Lighthouse C Forum 5
12:00 PM - 1:00 PM	LUNCH with Breakout Groups - in Grand Ballroom and Lighthouse C	
1:00 PM - 2:00 PM	Breakout Session #1 <ul style="list-style-type: none"> ● The Brotherhood ● Content Clubhouse ● Whitehouse Advocacy Kickoff ● META Glasses & other assistive devices presentation 	Forum 5 Forum 1 Forum 6 Forum 2
2:00 PM - 3:00 PM	Breakout Session #2 <ul style="list-style-type: none"> ● Current Assistive Technology ● HPS 101* ● Pulmonary Wellness ● META Glasses & other assistive devices up close look 	Forum 1 Forum 3 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 ● HPS Subtypes discussion group (excluding 1,2 & 4) ● Social Life with HPS 	Forum 1 Forum 2 Forum 5 Forum 3
4:00 PM - 5:00 PM	Breakout Session #4 <ul style="list-style-type: none"> ● OBGYN Virtual Office Hours with Dr. Merideth * ● "GI" Wish I Felt Better ● Mental Health & Sensory Disabilities ● Paint Party ● Content Clubhouse 	Forum 5 Forum 2 Forum 3 Lighthouse C Forum 1
7:00 PM - 11:00 PM	Celebration Dinner (with cash bar, credit not available) and Group Picture	Grand Ballroom

Sunday, April 6th

Time	Session	Room
8:00 AM - 8:30 AM	Sunrise Session	Lighthouse C
8:00 AM - 12:00 PM	Store and AID help desk	Lighthouse A
8:30 AM - 9:30 AM	Continental Breakfast	Grand Ballroom
9:30 AM - 10:00 AM	Seeing the Inside of Research	Grand Ballroom
10:00 AM - 10:30 AM	HPS Awareness Celebration/6 minute walk	Grand Ballroom
10:30 AM - 11:15 AM	HPS Overview* <ul style="list-style-type: none"> • Dr. William Gahl, NHGRI, NIH 	Grand Ballroom
11:15 AM - 11:45 PM	HPS Pulmonary Health <ul style="list-style-type: none"> • Dr. Jesse Roman, Thomas Jefferson University Hospital, PA 	Grand Ballroom
11:45 AM - 12:30 PM	Inflammatory Bowel Disease of HPS <ul style="list-style-type: none"> • Dr. Louis Cohen, Mount Sinai, NY 	Grand Ballroom
12:30 PM - 1:30 PM	LUNCH	Grand Ballroom
1:30 PM - 2:00 PM	HPS Kidney Report* <ul style="list-style-type: none"> • Dr. Wendy Introne, NHGRI, NIH 	Grand Ballroom
2:00 PM - 2:30 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 	Grand Ballroom
2:30 PM - 3:00 PM	The Secret Sauce: What NonProfits Need to Think About on the Road to a Cure <ul style="list-style-type: none"> • Dr. Josh Fessel 	Grand Ballroom
3:00 PM - 3:45 PM	How do we stop bleeding? <ul style="list-style-type: none"> • Donna Appell, RN, Executive Director of HPS Network 	Grand Ballroom
3:45 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 	Grand Ballroom
4:15 PM - 4:30 PM	Closing <ul style="list-style-type: none"> • Donna Appell, RN, Executive Director of HPS Network 	Grand Ballroom

*these sessions will be presented live via ZOOM