



2024 Conference Agenda

Friday Afternoon, April 5th

Time	Session	Room
1:00 PM - 5:00 PM	Conference Registration and Store	Lighthouse A
1:00 PM - 5:00 PM	AID Help Desk	Lighthouse B
3:00 PM - 4:00 PM	HPS First Aid/How to stop bleeding with Donna and Ashley Appell	Lighthouse C
4:00 PM - 5:00 PM	Ice Breaker and New Member Welcome	Lighthouse C
5:00 PM - 6:00 PM	'TED Talks' / A Rare Story	Lighthouse 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 Morning, April 6th

Time	Session	Room
7:30 AM - 8:30 AM	Continental Breakfast	Ballroom
8:30 AM - 9:00 AM	Welcome	Ballroom
8:00 AM - 1:00 PM	AID Help Desk & HPS Awareness Day Set-up	Lighthouse B
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 4 Lighthouse C Forum 8 Forum 3
12:00 PM - 1:00 PM	LUNCH with Breakout Groups	in Ballroom and Lighthouse C
1:00 PM - 4:00 PM	AID Help Desk & HPS Awareness Day Set-up	Lighthouse B
1:00 PM - 2:00 PM	Breakout Session #1 <ul style="list-style-type: none"> ● Interactive Pulmonary Wellness ● Building Resilience In Your Child ● Non-Lung Disease Subtypes Group Discussion ● The Brotherhood 	Forum 7 Forum 8 Forum 3 Forum 4
2:00 PM - 3:00 PM	Breakout Session #2 <ul style="list-style-type: none"> ● Daily Living for those with Low Vision ● “GI” Wish I Felt Better Group Discussion ● Being a Parent with HPS- talking with your loved ones 	Forum 4 Forum 3 Forum 8
3:00 PM - 4:00 PM	Breakout Session #3 <ul style="list-style-type: none"> ● Pre & Post Lung Transplant Panel ● HPS Awareness Through Legislation ● HPS 101 	Forum 3 Forum 4 Forum 8
4:00 PM - 5:00 PM	Breakout Session #4 <ul style="list-style-type: none"> ● OBGYN Office Hours with Dr. Merideth ● Office Hours with Rick Bowman ● Tips for being a Caregiver Panel ● Paint Party (sign up required) 	Forum 7 Forum 4 Forum 8 Lighthouse C
7:00 PM - 11:00 PM	Celebration Dinner (with cash bar) and Group Picture	Ballroom

Sunday, April 7th

Time	Session	Room
8:00 AM - 8:30 AM	Sunrise Session	Lighthouse C
8:30 AM - 9:30 AM	Continental Breakfast	Ballroom
10:00 AM - 4:00 PM	AID Help Desk & HPS Awareness Day Set-up	Lighthouse B
9:30 AM - 10:30 AM	How We See <ul style="list-style-type: none"> ● Elizabeth Schafer 	Ballroom
10:30 AM - 11:15 AM	HPS Overview <ul style="list-style-type: none"> ● Dr. Wendy Introne, NHGRI, NIH 	Ballroom
11:15 AM - 12:00 PM	Updates from Cellphire Research: HPS Platelets <ul style="list-style-type: none"> ● Dr. Allan Alexander, Cellphire 	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
12:30 PM - 1:30 PM	LUNCH	Ballroom
1:30 PM - 2:00 PM	Updates on HPS Gene Therapy Research <ul style="list-style-type: none"> ● Dr. Gustavo Nieto, NHGRI, NIH ● Mahin Hossain, NHGRI, NIH 	Ballroom
2:00 PM - 2:30 PM	Pre and Post Lung Transplant Care Management <ul style="list-style-type: none"> ● Dr. Luis Angel, NYU Langone Transplant Institute 	Ballroom
2:30 PM - 3:00 PM	Inflammatory Bowel Disease of HPS <ul style="list-style-type: none"> ● Dr. Louis Cohen, Mt. Sinai, NY 	Ballroom
3:00 PM - 3:30 PM	Dermatological Issues of Albinism <ul style="list-style-type: none"> ● Dr. Sharon Glick, SUNY Downstate Medical Center 	Ballroom
3:30 PM - 4:00 PM	HPS Standard of Care <ul style="list-style-type: none"> ● Dr. Samuel Seward, Chair of the HPS Network Scientific Advisory Board 	Ballroom
4:00 PM - 4:30 PM	Closing <ul style="list-style-type: none"> ● Donna Appell, RN, Executive Director of HPS Network 	Ballroom