

DRAFT 2024 Conference Agenda



Friday Afternoon, April 5th

Time	Session	Room
2:00 PM - 5:00 PM	Conference Registration	TBD
3:00 PM - 4:00 PM	HPS First Aid/First Line Treatment/How do you stop bleeding? with Donna and Ashley Appell	TBD
4:00 PM - 5:00 PM	Ice Breaker and New Member Welcome	TBD
5:00 PM - 6:00 PM	'TED Talks' - Rare Stories	TBD
7:00 PM - 8:00 PM	Dinner	Ballroom
8:00 PM - 10:00 PM	Year in Review	TBD
10:00 PM - 11:00 PM	Let's head to the bar!!!	TBD

Saturday Morning, April 6th

Time	Session	Room
7:30 AM - 8:30 AM	Continental Breakfast	TBD
8:30 AM - 9:00 AM	Welcome	TBD
9:00 AM - 11:00 AM	Family Album	TBD
11:00 AM - 12:00 PM	Breakout Groups <ul style="list-style-type: none"> ● Adults ● Parents ● Partners & Other Supporters ● LGBTQIA+ 	TBD TBD TBD TBD
12:00 PM - 1:00 PM	LUNCH with Breakout Groups	TBD
1:00 PM - 4:00 PM	AID Help Desk & HPS Awareness Day Set-up	TBD
1:00 PM - 2:00 PM	Breakout Sessions <ul style="list-style-type: none"> ● Interactive Pulmonary Wellness ● HPS 101 ● Non-Lung Disease Subtypes Group Discussion 	TBD TBD TBD
2:00 PM - 3:00 PM	Breakout Sessions <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 	TBD TBD TBD
3:00 PM - 4:00 PM	Breakout Sessions <ul style="list-style-type: none"> ● Pre & Post Lung Transplant Panel ● Policy Advocacy 101 ● Building resilience in your child 	TBD TBD TBD
4:00 PM - 5:00 PM	Breakout Sessions <ul style="list-style-type: none"> ● OBGYN Office Hours with Dr. Merideth ● The Brotherhood ● Tips for being a Caretaker Panel ● Paint Party (sign up required) 	TBD TBD TBD TBD
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	TBD
8:30 AM - 9:30 AM	Continental Breakfast	Ballroom
9:15 AM - 9:30 AM	Opening Science Sunday <ul style="list-style-type: none"> • Donna Appell, RN, Executive Director of HPS Network 	Ballroom
9:30 AM - 10:15 AM	How We See Presentation <ul style="list-style-type: none"> • Elizabeth Schafer 	Ballroom
10:15 AM - 11:00 AM	HPS Overview <ul style="list-style-type: none"> • Dr. Wendy Introne, NHGRI, NIH 	Ballroom
11:00 AM - 12:00 AM	Management of HPS Bleeding <ul style="list-style-type: none"> • TBD Updates from Cellphire Research <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	What we know about the Inflammatory Bowel Disease of HPS <ul style="list-style-type: none"> • Dr. Louis Cohen, Mt. Sinai, NY 	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	Updates on HPS Gene Therapy Research <ul style="list-style-type: none"> • Dr. Gustavo Nieto, NHGRI, NIH • Mahin Hossain, NHGRI, NIH 	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 with Donna Appell, RN, Executive Director of HPS Network	Ballroom