Primary Hyperoxaluria (PH) Workshop & Hyperoxaluria Global Alliance (HGA) Meeting held in Prague, Czech Republic

From June 26th till 28th, 2026
Organized by the Oxalosis and Hyperoxaluria Foundation (OHF).

Place: Location: Hermitage Hotel, Prague

Name: Nibedita Saha & Krishna Kanta Saha (Parents of KANISHKA BINAYAK SAHA)

"Professional Workshop on Saturday evening, June 27
Hyperoxaluria Global Alliance (HGA) meeting in Prague, held on June 28, 2026, in Prague, Czech Republic."
organized by the Oxalosis and Hyperoxaluria Foundation (OHF).

Purpose of attending this programme:

- We are truly honored to accept the invitation from Kim Hollander through Kari Bloom, OHF to attend the Professional Workshop held on Saturday evening, June 27, 2026, as well as to meet with our beloved son KANISHKA's Doctor (Dr. Jakub Zeig) from Motol Hospital
- Hyperoxaluria Global Alliance (HGA) meeting in Prague, held on June 28, 2026, in Prague, Czech Republic.
- We look forward to expressing our commitment to the PH community and sharing the journey we've had with our son, Kanishka Binayak Saha, as well as our united efforts to eradicate Hyperoxaluria.
- As parents, we are heartbroken by the loss of our cherished only child, Kanishka, who was just 9 years and 7 months old, to this devastating illness. In honor of our dear Kanishka and to sustain his legacy, we founded the Kanishka Binayak Memorial Foundation. We received our invitation also on behalf of "Kanishka Binayak Memorial Foundation". Our goal is to raise awareness and provide vital information and support to the PH Global Alliance.
- To gather additional insights regarding the Unmet Need, Challenges, Opportunities, and Priorities for Public Health Advocacy.

List of the session(s) which were most helpful to me in achieving our "Kanishka Binayak Memorial Foundation's" objective(s).

All the sessions were interesting and informative to us that we attended on 27.6.2026.

- Metabolic Dysfunction-Associated Steatotic Liver Disease in a Mouse Model of Primary Hyperoxaluria Type 1
- Real World Use of siRNA
- Lumasiran Treatment Outcomes in Infants with Primary Hyperoxaluria Type 1
- Functional and In Silico Characterization of Common AGXT Variants as Potential Modifiers of Primary Hyperoxaluria Type 1
- Coincidentally, that day I received a WhatsApp call from India (A Parent of a Girl Child, whose daughter is a PH1 patient and she is under the treatment of Dr. Nageswara Pamidi Reddy. He gave the contact of Kanishka Binayak Memorial Foundation to get the proper guidelines for getting the medicine "Lumasiran". As it is not available in India (Asia). While on my return journey, I texted Kim about it and gave the important guidelines on how to get in touch with **Alnylam Pharmaceuticals**. Finally, get connected and I was able to get connected with Dr.to complete the protocol of receiving the medicine in India. It was really a useful and significant meeting for us as parents, as well as for our Kanishka Binayak Memorial Foundation
- **Significant Training on how to do the Advocacy and how to educate people about the awareness of PH – Mentored by Sabine Hahn, PhD, Senior Patient Engagement Manager | Biomedical Scientist | Patient Advocate**

What information have I gathered?

The main information and knowledge that I have acquired from this PH Global Alliance and the Professional Workshop on Primary Hyperoxaluria in Prague

Expressed with **HOPES** (**H**yper **O**xaluria **P**atients need **E**mpathy, not **S**ympathy)

Our beloved KANISHKA is busy preparing the structural Lego Station on his 8th Birthday after returning from Hemo Dialysis before Dr. Zeig visited his room at Motol Hospital in 2009, 16th October.

Our beloved KANISHKA celebrated his 8th Birthday with Dr, Zeig at Motol Hospital in 2009, 16th October

SPECIAL THANKS TO
KIM HOLLANDER
&
JULIE BERTARELLI
&
KARI BLOOM

THANKS TO ALL PH MEMBERS FOR
ALLOWING US TO JOIN
THE PH GLOBAL COMMUNITY

KANISHKA BINAYAK SAHA'S
PARENTS

KRISHNAKANTA SAHA (FATHER)
NIBEDITA SAHA (MOTHER)