

“Our Lives with Hemophilia: The Stories of Vaibhav and Paul” Spokesperson Biographies

Alok Srivastava, M.D.

**Member, Executive Committee, World Federation of Hemophilia (WFH)
Professor, Christian Medical College Hospital, India**

Dr. Srivastava serves on the WFH Executive Committee. He also teaches and practices in the Clinical Haematology Department at the Christian Medical College Hospital in Vellore, India.

Paul Wilton

24-Year-Old with Severe Hemophilia A

Member, Blood Safety Committee, Canadian Hemophilia Society

Paul Wilton is a person with severe hemophilia A from Ontario, Canada who is currently working in recruitment at his local university. He learned at a young age some of the challenges associated with hemophilia A, including sitting out from contact sports and physical education class. However, Paul did not let these challenges control his life. Participation in hemophilia camp helped him meet other kids like him with whom he could share his experiences and – because he learned how to self-treat his hemophilia while there – afforded him independence. The positive impact of camp and his new friends motivated Paul to become a camp director.

To manage his hemophilia A today, he infuses prophylactically with factor replacement therapy and regularly meets with his comprehensive care team at his local hemophilia treatment center (HTC). Paul enjoys canoeing, golfing and spending time with friends and would like to pursue a graduate degree with the goal of teaching high school or college someday. Paul is committed to staying involved in advocacy work because he wants to help others like him around the world receive proper education about and care for hemophilia. He is currently an active member of CHS, where he volunteers on the organization’s Blood Safety Committee, and is also a member of several other regional and local hemophilia organizations.

Vaibhav Nehra

22-Year-Old with Severe Hemophilia A

Chartered Accountancy Student, India

Vaibhav Nehra is a person with severe hemophilia A from New Delhi, India who is currently pursuing certification in chartered accountancy. Because of a low level of awareness about hemophilia, as well as few resources to treat it in his country, as a child, he was encouraged by his parents and healthcare professionals to avoid physical activity because they did not want him to get hurt or develop bleeds. He would miss weeks – sometimes even months – of school due to complications from his hemophilia. While this sometimes made Vaibhav feel frustrated and isolated because he could not have the same experiences of other children his age, he now enjoys spending time with family, friends and members of the local hemophilia society. To treat his hemophilia today, he infuses with on-demand factor replacement therapy and visits his local HTC, or the nearest hospital, when needed. In his spare time, he enjoys listening to music, writing poetry and reading novels. Vaibhav remains optimistic about his future because with proper medical care and prevention, he hopes to one day start his own auditing practice.

Hari Om Nehra
Vaibhav's father

Hari Om Nehra is Vaibhav's father and a member of the Indian Air Force. Vaibhav's diagnosis was the first time that he learned of severe hemophilia A – a condition that would ultimately have a profound impact on not only his son, but the entire family. Over the years, he and his wife worked diligently to educate themselves and their community about the condition, relying on resources such as the local hemophilia society and healthcare professionals who worked at the army facility at which Hari was employed.

Sneh Lata Nehra
Vaibhav's mother

Sneh Lata Nehra is Vaibhav's mother and a teacher. She sometimes found it challenging to raise a son with hemophilia, a condition that was not well understood by her family's neighbors and other local community members. As a working mother, she often was faced with the hard decision to leave her son at home alone when he was immobilized from bleeds, as both she and her husband had to work to support their family. Sneh feels very fortunate that Vaibhav has had access to care and treatment over the years – something she realizes many other people with hemophilia in India are not as fortunate to receive – and is excited about the promising future in store for her son.

Pam Wilton, R.N.
Paul's mother

Pam Wilton is Paul's mother and a registered nurse. Like many parents of children with hemophilia, she and her husband were concerned when their son Paul was first diagnosed. As a symptomatic carrier of hemophilia and a healthcare provider, Pam could empathize with the challenges she knew he would face throughout the years. At first, she wanted to protect him and had difficulty sending him off to school or leaving him with a babysitter. However, thanks to a variety of resources available to treat Paul's hemophilia – from recombinant therapies, to support and educational programs from local hemophilia organizations, to comprehensive care provided by the HTC – Pam is confident her son's health is in good hands. Pam now volunteers in her local bleeding disorder community, provincially and nationally, working to educate the broader public about hemophilia and other bleeding disorders.

For more information about hemophilia and to view the video podcast series, please visit wfh.org/TFAseries.