

Dear CDKL5 South Asia members,

We are thrilled to announce that Dr. Lokesh Lingappa with Dr. Prasanthi Aripirala has joined CDKL5 South Asia Foundation as the Chief Medical Officer. [We recently held a virtual meet and greet with the doctors on January 27, 2023, and it was well received in the community.](#) We welcome them on board and look forward to working together to improve the lives of CDKL5 patients in South Asia. The video recording of the zoom meeting will be uploaded and shared shortly.

As part of our next steps, we are building a registry, and the first Center of Excellence (COE) for CDKL5 in the South Asian region is at Rainbow Children's Hospital. Our aim is to bring clinical trials to this region, and we are excited about the possibilities that lie ahead. With a projected incidence rate of 1:40,000, the South Asian region's population is four times the population of the USA, making it an important region from a pharmaceutical market perspective.

Registry questionnaire links: [CDKL5](#); [Dravet/LGS/no diagnosis](#)

We invite you to join us on social media and stay updated on our progress. You can find us on social media at:

[fb.com/cdkl5southasia](https://www.facebook.com/cdkl5southasia),

[ig.com/cdkl5southasia](https://www.instagram.com/cdkl5southasia), and

[twitter.com/cdkl5southasia](https://twitter.com/cdkl5southasia).

Social media pages managed by [PixelFox](#).

We also want to share the [Ulysses Lab](#) podcast recorded in Hindi to help you better understand CDKL5 and its challenges. You can listen to it here:

[https://open.spotify.com/episode/6Gi0wn2GS8noi7ucdZwqrY?si=s4xkLq8KTuuS6j6R\\_2MJwQ&nd=1](https://open.spotify.com/episode/6Gi0wn2GS8noi7ucdZwqrY?si=s4xkLq8KTuuS6j6R_2MJwQ&nd=1)

We know how challenging it can be to care for a loved one with CDKL5. Shipli Khera, mom to Hiya, shared her experience with us: *"Till Hiya turned 3 we were in India & we had no diagnosis let alone a support system. It even took me 2 more years after moving to the USA to find her diagnosis & from there it was a whole another journey. It's good to know the diagnosis & what options are available to families & resources to further support are within reach now. The patient community is growing. Having a patient community around us, and a center of excellence are important first steps toward clinical trials. This is an important milestone. I am excited about more to come."*



(In picture, Hiya (center) with her parents Shilpi and Rishi)



(CDKL5 South Asia team in Cambridge, MA, USA attending the CDKL5 Forum hosted by the [LouLou Foundation](#) in November 2022. From left to right, Sumit Pokhariyal, Jainu Jogani, Dr. Vivek Jogani, Dr. Akulji Mehta, Saksham Pokhariyal.



(In this picture are teams - CDKL5 South Asia, [Hope4Harper-CDKL5](#), [CDKL5 UK](#))



(From left to right, Penny Howard, Dr. Dan Lavery (CSO, LouLou Foundation), Jainu Jogani)

If you have any questions or would like more information, please reach out to Mr. Sumit Pokhariyal at [support@cdkl5southasia.com](mailto:support@cdkl5southasia.com).

Thank you for your continued support.

Best regards,  
CDKL5 South Asia Foundation Team

