



IPWSO
International
Prader-Willi Syndrome
Organisation

IPWSO Leadership ECHO summary

January, 2022: Developing a National Association

"Good session for any country that do not have their parent group or association yet"

"Great presentations also to rethink what we have achieved already and what we can improve further... thank you!"

~Leadership ECHO survey responses

Our first IPWSO ECHO of 2022 was a very useful and informative meeting of the Leadership ECHO group held on January 11th. In this session Azhar Talib, President Persatuan Sindrom Prader-Willi Malaysia presented *"Developing a National Association"*.

His presentation illustrated the importance of setting clear Vision, Mission and Objective, the value of having a strategic Roadmap, developing an Action Plan, and how to mobilize, empower and build up a network. Prader-Willi Malaysia has had great success since it began in 2016 and is a fine example of the impact a PWS Association can make.

One of the particularly important points Azhar made is the need for a clear vision to help inform your recruitment. Through teamwork and by raising awareness of Prader Willi syndrome, the Association has increased support and membership.

Enlisting many different groups is crucial, and Azhar emphasised work with allied health professionals and their importance in providing a lifelong support, and also touched on some of the funding issues in Malaysia and the role of the pharmaceutical industry in developing research and treatments, the importance of the government and also the importance of corporate groups, with the long term plan to try and improve the lives of people with Prader Willi syndrome and their families. The Association plays a central role in bringing these different groups together, and through technology it is also part of the wider global network.

We hope you enjoyed the presentation; if you would like to revisit it or if you weren't able to join us on the day, here is the video link so you can view in your own time.

Azhar Talib: [Developing a National Association](#)

The PDF is available [here](#).

We also heard from Shikha Metharamani, Indian Prader Willi Syndrome Association. Shikha will gave us an overview of the Association and shared some of the challenges their patient support group faces.

India consists of many different races and religions and it is important that the Association represents everyone in India. The Association supports parents and families. Initially in India the diagnosis was actually happening later in people's lives, so the founding families were of older children. They now target the paediatric community, the medical community, and have seen an improvement and are now seeing diagnosis earlier in life, an enormous achievement!

Shikha also talked about their work to get Prader Willi syndrome recognised as a rare disorder in India which was vital in developing awareness. The two talks together beautifully illustrated the challenges faced and that many people in the world face in raising awareness and gaining support for PWS.

Shikha's PDF is available [here](#).

Upcoming Leadership ECHO sessions

February 1st,
2022

The future of
research in PWS

Prof Maithé Tauber, Reference Centre for
Prader-Willi syndrome, France

Thank you very much to everyone who attended the session and participated. We look forward to seeing you again at the next session on the 1st of February.

Ends.