A Ruby celebration at the House of Lords

Friday 15 November, 2024

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Forty years ago this month a young mother sat at her kitchen table with a notepad and pen as her infant son slept. She'd just received the devastating news that her baby had **nystagmus**, a complex, incurable eye condition. She'd never heard of nystagmus before and had come away from the hospital with scant information, most of which turned out subsequently to be inaccurate.

From self-help group to national charity

Fast forward to 2024 and the self-help group Vivien Jones started that night has become the **Nystagmus Network**, a national registered charity with a huge digital reach, providing support and a wealth of information to families and adults diagnosed with nystagmus.

"The charity is called the Nystagmus Network for a reason – it brings people together."

Still very much at the helm and leading the charity's drive for research, Vivien has seen many changes over the years as she gathered together first volunteers, then trustees and, finally, staff. At the heart of its work are the same values she wanted to share back in 1984.

She says: "I like to think that the best of those early days – the emphasis on personal contact – has survived in the DNA of the charity."

A very special occasion

The Nystagmus Network has been marking its fortieth year throughout 2024, with campaigns, events, competitions and 40 years of nystagmus stories. The pinnacle of these celebrations is the Ruby Anniversary Reception, taking place on Tuesday 19 November. Kindly sponsored by The Lord Blunkett, the charity will welcome some very special guests to the River Room at the House of Lords. Those attending include Vivien's family, including her son, Sam, her fellow trustees, current and former volunteers and staff team members, supporters, donors and fundraisers alongside the researchers, academics and clinicians who have been with the charity along the way.

Marsha accepts ambassadorial role

Among them will be **Marsha De Cordova MP**. Marsha has nystagmus herself and is a strong advocate of rights and opportunities for disabled and, especially, blind and partially sighted people. She has long been a stalwart supporter of the charity and recently consented to become a Nystagmus Network ambassador. The charity is thrilled to have her continuing support.

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