A wired world, coupled with shifts in what many people seek in support, has created a challenging environment for many of ASHA’s HELP Groups. For example, the attendance of Tampa HELP (one of the oldest of the ASHA-affiliated groups) has declined to an extent that the group decided to suspend operations.

The group’s coordinator, Susan Martin, chatted with The Helper recently and reflected on more than 25 years of offering support and service through her group. Despite changes to the HSV support landscape, she concludes the essential messages needed by patients and partners remain much the same.

The Helper: Over the last several years, a number of HELP Groups have reported declines in attendance. Why do you think that’s happening?

Susan Martin: With our group, attendance started falling off as soon as the Internet really took off. We were at our peak in the late 80s through early 90s, when up to 30 people attended meetings. More recently, we’ve had fewer than five. Being online makes it much easier for people to connect, especially locally.

The number of HSV groups and forums currently available online is large, and seems to be growing. Can their success perhaps be explained in part because chatting with someone on the Internet seems less daunting than attending a meeting in person?

I think so. Over the years I’ve had people hiding in the bushes outside the building, to make sure we’re normal people going inside! I do understand that it is hard to come into a group setting like that. Still, these days there are many herpes social groups that are thriving and involve face-to-face meetings, whether it’s dating or just getting a group together and going to dinner.

Talk about the impact of herpes groups that focus more on social activities, including dating – is the traditional ASHA model of education and support still as relevant?

I think the education piece remains critical, yes. When dealing with herpes, people sometimes think if they have a social outlet, that’s really all they need. It’s still important for people to learn all they can about HSV, because if you get the education it empowers you to go out there and be who you want to be. The more someone learns about herpes, the less scary it seems, so getting the right information about testing, treatment risk reduction, and so on should be an essential component of any herpes support or social outlet.

Thinking back on your years of service, what is the most important message people need to hear when first diagnosed with herpes?

First, they need to realize how normal herpes is, how common this virus is. When someone is initially diagnosed with herpes they tend to think they’re unique, they’re the only one who’s gone through those feelings and emotions. It’s easy to feel like it’s you against the world, so an
important first step is in understanding just how prevalent HSV is.

Of course, a big problem there is the majority of people who have the virus are unaware. I think this is where support groups are important because it allows people to see normalcy—others with herpes who are dating whomever they choose, getting married, having children, and living their lives. Having herpes precludes none of that. It’s important not to feed a sense of isolation.

Read more about ASHA HELP Groups at [ASHA’s website](https://www.asha.org). Also visit ASHA’s [HSV Information and Support Forum](https://www.asha.org).