

## MEET OUR NEWEST TEAM MEMBER



Aloha! Please welcome Ginger Knowles as the Hawaii and Pacific Deaf-Blind Project's Family Support Specialist. Ginger has over 20 years experience working with our youth in early childhood education and special education. She is a graduate from Chaminade University of Honolulu with a degree in Early Childhood Education and a dual licensure degree in Special Education & Elementary Education-Mild to Moderate K-12. Ginger currently resides on the west side of the island of Oahu with her family. When Ginger is not keeping busy as a caregiver to her son who has mild to moderate unilateral hearing loss, autism, and trisomy 12p; you can find her volunteering in the community, shopping, or cooking healthy food.

## TRISOMY PROCLAMATION

Aloha, my name is Ginger Knowles. I am a member of the Support Organization for Trisomy 18, 13 and Related Disorders (SOFT) which is a registered nonprofit charity in Hawai'i. On behalf of The Support Organization for Trisomy (SOFT), this is the second year that I have requested that March be proclaimed as Trisomy Awareness Month in Hawai'i.

A Trisomy is the presence of a single extra chromosome in any one of an individual's 23 pairs of chromosomes. This can be represented in a full trisomy, mosaic trisomy, or partial trisomy. The most common trisomies are Trisomy 21 (Down Syndrome), Trisomy 18 (Edward Syndrome), and Trisomy 13 (Patau Syndrome). Down Syndrome affects 1 out of 800 live births, Trisomy 18 affects 1 out of 5,000 live births, and Trisomy 13 affects 1 out of 16,000 live births.

Only about 10% of our children with Trisomy 18 and 13 live to celebrate their first birthday. To avoid the pain of losing a child most families are given the recommendation to terminate or deliver the child early. This sets a tone of a non-survival rate for the child.

I have a son with an extremely rare chromosomal abnormality called Trisomy 12p. Trisomy 12p is when a portion of the short arm (p) of the 12th chromosome (12p) appears three times (trisomy) instead of twice in cells of the body. It is estimated that 1 out of 50,000 live births is affected by Trisomy 12p. There are only 40 medical documented cases of Trisomy 12p in the world. Most children do not survive after 5 weeks old. In most cases, Trisomy 12p is not inherited but the duplication can be passed on to their children.

My son does live with several disabilities resulting from Trisomy 12p. However, he is able to learn ASL, express himself, comprehend, and charm others with his personality. We are indeed grateful we did not take the recommendation to terminate our son's life for he is a happy and loving child. My son is a living example of having determination and beating the odds at a very young age. For these reasons, it is important to continue to spread awareness of Trisomy to our community in Hawai'i.



*Image Descriptions: Ginger with glasses and pearl earrings smiling at camera; Ginger and her son who is wearing glasses and using a pacifier; Ginger and her family with matching green plaid outfits; Ginger holding the proclamation at the State Capital.*