

Palliative Care team supports Rhiannon and her mom Terena

For Terena Scott, parenting her daughter Rhiannon has been a long and winding road. As early as Rhia's first year of life, Terena knew that her development was unusual.

When Rhia was six, doctors diagnosed her with cerebellar atrophy, which included delayed development. A decade later, they discovered it was caused by a rare mitochondrial disorder that is not fully understood and has no treatment. The disease has since caused Rhia to lose most of her hearing and sight; ataxia (poor muscle control) makes walking, eating, and other daily activities a challenge.

Yet Terena and her daughter exude positivity. They have the same winning smile, share silly jokes via sign language, and are among the most determined people you will meet.

Terena, a special education teacher and writer, says, "I'm the kind of person who's like, 'All right, let's figure this out!'"

Figuring things out for Rhia has been challenging. Physicians still don't know what type of mitochondrial disease she has. Rhia is now part of the



The Mission Hospice palliative care team supports Rhia (R) and her mom Terena, who struggled to find help after they moved from Ukiah to the Bay Area to be closer to services.

After years of driving from their home in Ukiah for Rhia's appointments at Stanford, the pair moved to the Bay Area to be closer to support services. They are grateful that they found palliative care with Mission Hospice.

appointment. Within a week we had help."

"People think of palliative care as symptom management, but it's so much bigger than that. Part of it is mental health. Having the Mission Hospice team helps me not feel so alone. I can text (Nurse Practitioner) Michele (Cronin) with medical questions, talk to (Social Worker) Lucia Hollowell about the stress – it means so much."

Rhia's symptoms are so severe that no day program will admit her, so she is largely confined to her home in Belmont. A caregiver spends the day with her while Terena works, and visits from her two Mission Hospice volunteers are highlights of her week.

"People think of palliative care as symptom management, but it's so much bigger than that. Part of it is mental health. Having the Mission Hospice team helps me not feel so alone."

– Terena, mom of palliative care patient Rhia Scott

Undiagnosed Diseases Network, which convenes clinical and research experts to solve challenging medical mysteries. "All we know is that her disease is degenerative," says Terena. "We don't know how much more time she has."

"In fall of 2021, Rhia was in significant decline," says Terena. "I didn't know what was going on, and I was scared; I went online looking for resources. My friend called Mission Hospice, and within an hour we had scheduled an

Terena and Rhia... continued from front

Volunteer support for the family is so important, Mission Hospice matched Rhia with not one but two volunteers – both of whom are uniquely suited for this assignment. These volunteer visits provide important socialization for Rhia, who her mom says is “a social butterfly.”

Volunteer Melissa Stueve, a former audiologist, has a background in speech pathology and knows sign language – all useful in her work with Rhia. She says their weekly visits typically include a ritual of selecting and reading some books, coloring together, and organizing her collection of stuffed animals.

“I always have a good time hanging out with her,” says Melissa. “Rhia has a great sense of humor and loves to laugh with me. I feel so privileged to be let into their home and given an opportunity to visit. Sometimes we color, sometimes we read; either way, I know it will be a bright spot in my day.”



Volunteer Amanda Kanaday, who works as a registered behavioral technician, says that “volunteering with Mission Hospice has given me a sense of my purpose in the world. It made me realize this is what I want to do with my life.” In addition to her full-time job, she’s now studying for her Master of Social Work (MSW) degree – and still makes the time to volunteer.

“I’m so blessed and grateful that I get to work with everyone at Mission Hospice,” Amanda says. “Rhia is the sweetest person you could ever meet. She’s just the light of your life.”

In addition to being a companion for Rhia, Amanda has become an important part of Terena’s support system – checking in on her emotions and what she needs for support. They connected over many things, including a love of dance and yoga, as well as the discovery that they lived in Ukiah at the same time, but didn’t know each other.

Terena would be the first to say that living with a medical mystery is overwhelming. The stress and uncertainty pile up,



Volunteer Amanda Kanaday often reads and colors with Rhia on her weekly visits, giving her some much-needed socialization.

and having the Mission Hospice palliative care team on their side helps both of the women keep their amazing smiles.

“Even though Rhia doesn’t fit into any boxes,” says Terena, “Mission Hospice said, ‘let’s see what we can do.’ I just appreciate so much their willingness to try. It all helps me not feel so alone – that’s huge. And Rhia just loves Amanda and Melissa.”

Years ago, doctors told Terena that her daughter would be lucky to live to 20. Rhia just celebrated her 28th birthday; Melissa joined in the festivities, as did Cinderella – a special treat for the birthday girl, who loves princesses.

Terena has learned to celebrate what they can. “I’ve made peace with the fact of Rhia’s death,” she says. “I’m more afraid that she will suffer. Her speech is so slurred that sometimes even I can’t understand her. Her hands are so shaky she rips her beloved books. I’m afraid she’s going to lose more and more of what she loves, and I will not be strong enough to help her with that.”

“Mission Hospice helps me manage stress, allows me the chance for some self-care, and just helps make this less overwhelming,” says Terena. “I don’t feel like I’m battling this all by myself.” 🍌

Terena is finishing a memoir of Rhia’s first 18 years, [Raising Rhia](#), and blogs at [TerenaScott.wordpress.com](#).

Sharing expertise on end-of-life care with students worldwide

Mission Hospice clinicians provide continuing education for healthcare providers, internships for nursing, social work, chaplaincy, and counseling students, and in-services for staff at care homes and assisted living facilities.

This training is often close to home, but as in the case of a recent panel discussion, it can make connections on the other side of the world.

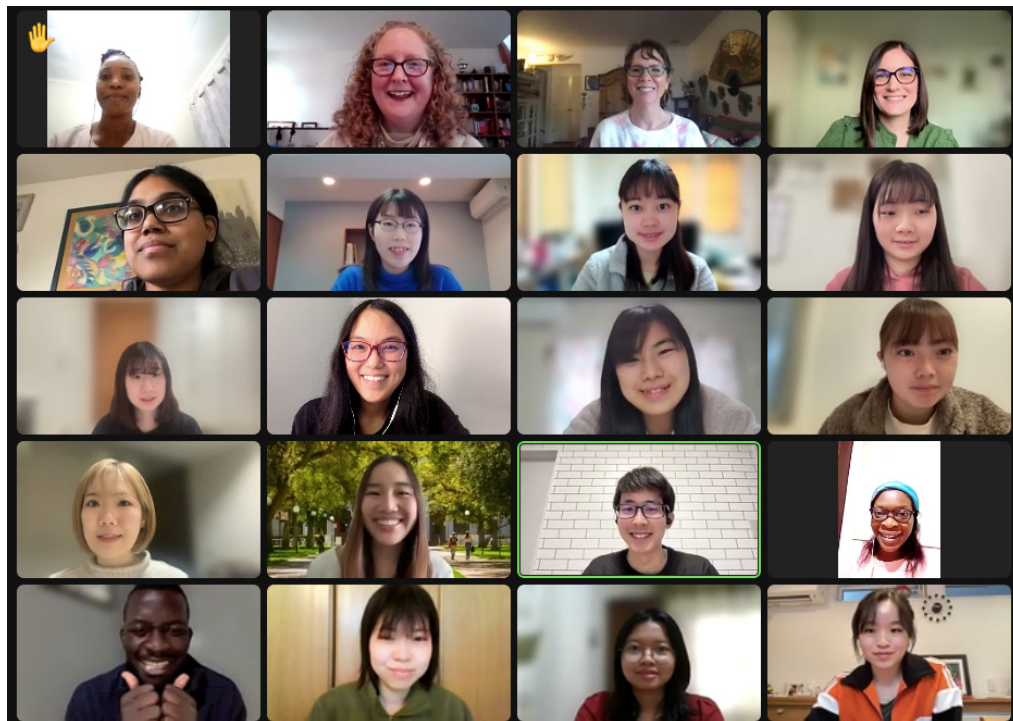
Helping us make these connections is our partner VIA (formerly Volunteers in Asia), an organization started at Stanford University that promotes experiential learning, cross-cultural understanding, and partnerships in the global community. Twice a year, VIA's Exploring Health Care program convenes 15-25 students from medical universities around the world to explore a range of health care topics.

As part of this program, a panel of experts from Mission Hospice spent time with 15 medical, nursing, and pharmacy students from Japan, Myanmar, and Zambia. The team (Bereavement Manager Christine Kovach, Nurse Gabby Jimenez, Spiritual Counselor Gloria Thomas, and Palliative Care Social Worker / Bereavement Counselor Lucia Hollowell) described their roles, discussed how hospice and palliative care supports patients and families, and answered the students' questions.

Lucia Hollowell explained that she appreciates being able to see the whole person during home visits. "We get to visit patients in their homes, which provides a different picture than the tiny window we see in the hospital. We see who they are, what their interests are, what their support system looks like. They are much more than their disease or their diagnosis. We can see them as human beings that are worthy of respect and really good care. They will then internalize that, and it can lead to better outcomes."

Program Director Lina Yamashita said the participants' training doesn't include much education about hospice and interdisciplinary care. They appreciated learning the difference between the medical goal of curing and the comfort goal of hospice.

of the belief that the things that we do and face when we are dying can affect our next life. Today I learned that the time we have at the end of life is essential and precious for everyone regardless of religion."



Mission Hospice clinicians recently spoke to medical, nursing, and pharmacy students from Japan, Myanmar, and Zambia, discussing how hospice and palliative care supports patients and families.

One attendee wrote, "I learned how deserving and rewarding working in hospice care is. I'm a Buddhist, and according to our religion, the time at the end of life is very important because

Our staff and volunteers are committed to sharing their expertise so that compassionate end-of-life care may be valued by and available to everyone – no matter who they are or where they live. 🍌



MISSION HOSPICE & HOME CARE

PENINSULA OFFICE 66 Bovet Road, Suite 100, San Mateo, CA 94402
SOUTH BAY OFFICE 688 Willow St., Suite A-2, San Jose, CA 95125
www.MissionHospice.org • 650.554.1000 • 408.554.2434

Inside – find your
 Summer 2023
 Community Connections

Nonprofit
 Organization
 US Postage
PAID
 Permit No. 63
 Burlingame, CA

Mission Hospice & Home Care serves patients and families in the San Francisco Peninsula and South Bay with personalized, compassionate end-of-life care and education. Founded in 1979, our local, independent nonprofit has supported thousands of patients and their families through illness and bereavement. Donations from the community support our exceptional care and educational programs, and help us serve people regardless of their medical coverage or ability to pay.

BOARD OF DIRECTORS

Sally Bergman
 Chair

Kate Jamentz
 Vice Chair

Dr. Robert Roe
 Past Chair

Jeff Gerard
 Treasurer

Judy DiPaolo
 Secretary

Mukund Acharya

Charlie Balquist

Stacy Blanchard

Lisa Burris

John Draper

James Hine

Dr. Michelle Pezzani

AUXILIARY PRESIDENT

Vibeke Gade

FOUNDERS

Helen Lagen

Mac Nash

CHIEF EXECUTIVE OFFICER

Dolores Miller

To add or remove your name from our mailing list, please call 650.554.1000.

INSIDE: Palliative Care team supports Rhiannon and her mom
 Sharing hospice expertise with students worldwide
 Fall Gala set for October 14 in Redwood City



Life is a CABARET!

Thank you to our sponsors and all those who attended, danced, and donated at our night of comedy and cabaret on April 29. The event raised more than \$80,000 for our patients and programs!

Thanks to the amazing cabaret artist Leanne Borghesi, we enjoyed a fun night of songs, dinner, dancing, and more.

More photos at
[Facebook.com/MissionHospice](https://www.facebook.com/MissionHospice).

