



Helping Children Thrive Through Care at Home

Henry's long blond hair bobs back and forth as he tries to hold his head up. Making a series of grunts, the two-year-old squishes up his face as he tries to stand up straight while clutching a giant foam block. Sitting beside him, with a hand on his back and his belly, Andrea Buteau, who has a doctorate in physical therapy, makes sure he doesn't fall.

While the task might seem simple, for Henry, it is anything but.

This is because Henry suffers from alternating hemiplegia of childhood (AHC), a one-in-a-million neurological disorder that presented when Henry was

just nine weeks old. The disease results in episodes of facial and limb paralysis, muscle weakness and seizures. As a result, Henry isn't yet strong enough to walk on his own. There is no cure for his condition, making home health care critical. That's where UVM Health Network - Home Health & Hospice's physical therapy for children comes in.

Several times a week, Buteau, a physical therapist with Home Health & Hospice's pediatric rehabilitation program, comes to Henry's home to work with him on strength-building exercises that are critical in fending off permanent damage from AHC. The program offers both occupational and physical therapy as well

The Pediatric Rehabilitation program offers therapeutic care, support and connection for children and their families.

as speech therapy for children in their homes. Eight clinicians, like Buteau, serve roughly 170 kids in Chittenden and Grand Isle counties.

Henry's mother, Mary Saladino, says that everyone at Home Health & Hospice and the pediatric rehabilitation program worked to ensure the right people were in place and that Henry got scheduled right away. "Henry's home health care team have quickly proven themselves to be his favorites," says Saladino.

"You made it!"

At a recent home visit, Buteau encourages Henry in his exercises. "Bend! Bend!

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Bend, Henry!" Buteau says, as Henry stretches his body back over a small cushioned chair to help maintain and build his torso muscles. "You made it!" cheers his mother. Henry giggles between grunts.

"He likes his squishy blocks," Buteau says. She incorporates toys into exercises that will help Henry's development. She wedges them into the door handle of the fridge, or in between other objects. Henry spots them and tries to pull them out, a fun game that also helps him develop strength and motor skills.

"The toy isn't a toy," Buteau admits with a grin. "It's a tool to engage him and get him to do what I need him to do, but also enjoy himself."

"You want to go somewhere?" Buteau asks him. Henry points to the walker and murmurs something that sounds a lot like "Yes." Henry's speech is severely limited, another impact of AHC.

“

We know he is getting such high-quality physical and occupational therapy without having to leave home. It's one of the few things that makes our life easier."

- Mary Saladino

Moments later, Buteau is protecting Henry from any potential falls as he crawls up to the walker, grabs a leg of the walker in each hand and starts the long process of lifting his little body.

"Yes!" Henry's mother exclaims as Henry lifts his chest off the ground.

Then, he manages to get high enough to stuff a knee under him, then another knee, and then a foot. Henry's progress looks exhausting, but he persists. The whole while, Buteau verbally encourages him while offering support when he falters.

Both Buteau and Henry's mother break into song, "The wheels on the bus go round and round. The wheels on the bus go step, step, step!"



Andrea Buteau, DPT, with Henry.

Before long, Henry has made it to the kitchen fridge. He's exhausted. He turns and flops into Buteau's arms, hugging her, both a gesture of affection and a chance to rest.

Allowing Families to Feel Supported and Connected

"We aren't just there to treat him as a patient. We are his friend, we are there to play with him and he's built relationships with us," Buteau says. "He's grown to love us."

For Henry's mother, this is exactly what they needed. "We never know when a seizure might hit," Saladino says. "Having home health care reduces the risk we'd have to cancel visits due to symptoms or the need to recover afterwards, because of the time and effort of travel to and from appointments is taken out of the equation."

Thanks to Buteau's physical therapy visits twice a week and weekly visits from her colleague, Rebecca Grimm, an occupational therapist and program team manager, Henry is getting care at home that wouldn't be possible otherwise.

Early Therapeutic Intervention, Better Outcomes

We know that there are neurological pathways that peak early in life," Grimm says. "No matter the issue or challenge, it gets a whole lot harder the older children get and those pathways become less and less accessible."

The visits also provided Henry with precious social interactions during the COVID-19 pandemic. Henry giggles when his mother tells him Buteau is coming to play or when he hears her voice as she arrives at their home.

"He responds so well to her instruction and she, in turn, respects what he communicates," Saladino says. "Andrea is patient and encouraging with Henry and understands his condition means that his body and abilities are a moving target. She has found the balance of pushing Henry and honoring his needs. □



McClure Miller Respite House

The McClure Miller Respite House opened its doors in Colchester seven years ago. Since then, hundreds of families from across Vermont and neighboring states have found comfort and support at the end of a loved one's life.

Vermont Runs for Respite House

The community raises more than \$75,000 for the McClure Miller Respite House.

For more than 30 years, hundreds of friends, families and supporters have participated in the annual Jiggety Jog & Fun Run in support of the McClure Miller Respite House. In 2022, participants raised more than \$75,000 to provide exceptional end-of-life care for the hundreds of Vermonters who come to the Respite House each year.

Every single dollar raised for the Respite House is put to use where it is needed most, including providing nearly \$1 million in charitable care each year.

Thank you to everyone who participated in the 2022 Jiggety Jog & Fun Run. Stay tuned for the announcement of the return to an in-person event in 2023!

About the McClure Miller Respite House

The Respite House is Vermont's only Medicare-certified inpatient hospice residence. Opened in 2016 at its Colchester location, the Respite House

has the feeling of home with its large living room, open kitchen, and spacious resident rooms — offering opportunities for residents and their loved ones to find treasured moments together.

Continuing the legacy of high-quality residential hospice care originally established by visionary community leaders in 1991, the Respite House was designed to be a home-away-from-home for people with terminal illness and their families. Care is offered in the privacy of one's room, which includes a fully accessible bathroom and shower. Most importantly, residents and their loved ones have the care and attention of skilled staff and volunteers around the clock so residents can focus on what matters most to them.

The Respite House remains true to its original mission by offering compassionate care and supportive services from dedicated staff and community volunteers during the last months, weeks, and days of people's lives while sustaining dignity, respect, and caring relationships. The Respite

"We cannot say thank you enough to the Respite House staff and volunteers for everything they did to make our father's last days comfortable. The opportunity to spend every day with my Dad, even the nights, gave me such peace because I was able to be with him right until the end.

- From the family of a resident who received care at the McClure Miller Respite House in Colchester, VT.



House welcomes residents of all ages and all walks of life, from all over Vermont and beyond its borders.

What Does Care at the Respite House Include?

A warm, compassionate, and personalized experience for people in the final stages of life and their families. Round-the-clock care, support, and resources include:

- Nursing Care
- Physician Visits
- Personal Care
- Emotional and Spiritual Support
- Grief and Bereavement Services
- Pain and Symptom Management
- Medication Management
- Medical Equipment
- Hospice Choir



“

Our mission truly lives in the hearts, minds and hands of our people. We cannot deliver on our mission — helping people live their fullest lives by providing high-quality, compassionate care wherever they call home — without our people.”

— Christine Werneke, Interim President & COO

HOME HEALTH & HOSPICE BY THE NUMBERS (2022)



234,695

Hours of care provided



4,101

Patients served, at all ages and stages of life



3,988

Days of care provided at McClure Miller Respite House



96,007

Home visits by caregiving team members

Our People Make the Difference

Our exceptionally dedicated staff of social workers, physical therapists and occupational therapists, speech language pathologists, grief and bereavement counselors, personal care attendants, licensed nursing assistants, nurses, nurse practitioners, physicians, spiritual caregivers and volunteers, provide care wherever you call home.

Our remarkable team makes a difference in the lives of our clients and their families every single day. We are deeply grateful for their constant commitment to our community.





"To have seven people loving you and caring about you... It's such a lovely way to be and then a lovely way to go.

— Erica Lustgarten

Erica Lustgarten reflects on the hospice care her mother received from UVM Health Network - Home Health & Hospice.



Hospice Care at Home Empowers End-of-Life Journey

Some people think that if you go on hospice, you're giving up," says Erica Lustgarten of Burlington. "But what I say is, 'if you go on hospice, you're surrounded by this blanket of love and care and basic medicine, and it's 10 times better than if you don't do it.' It's really the opposite of what everybody thinks. Instead of, 'I'm going to die,' it's more like, 'I'm going to be loved and nurtured and visited and cared for.' And who wouldn't want that?"

Lustgarten's mother, Albertine DeGroot, made the decision to seek hospice care from the University of Vermont Health Network - Home Health & Hospice at the age of 88, after a degenerative heart condition left her weak, tired and unable to continue living her full and high-energy life. She had declined a surgery, the outcome of which was uncertain for a woman of her age. And, with most of her immediate family members having already passed away, DeGroot also felt she had reached the end of her journey on earth.

DeGroot and Lustgarten experienced their first of many family losses in 1971, when the oldest of DeGroot's three children, Margit, passed away at the age of 18. After contracting scarlet fever at three months old, Margit suffered

brain damage, and half of her body was paralyzed. "She then went through the rest of her life as a handicapped child, which wasn't easy in the 1960s," Lustgarten recalls. "My parents worked really hard with her, giving her as normal a life as they could give her."

Lustgarten chokes back tears as she talks about her sister's death, which devastated the family. Then, she brightens as she describes the second phase of her parents' life together. "They went on to have this full and fabulous life. I mean, camping, hiking, tennis, skiing, biking. You name it, they did it. They went around the world six times." Their adventures came to an end when DeGroot's husband, Willem, died in 2015. When Lustgarten's brother, Ian, died of cancer in 2019, DeGroot started to shut down. "I just think losing these very important people was too much for her," Lustgarten says. Without the "big personalities" in her family, and weighed down by fatigue, "she had a broken heart, literally and figuratively."

When DeGroot's doctor referred her to Home Health & Hospice, DeGroot and Lustgarten found plenty of support on that journey through the hospice program. Lustgarten talks fondly about

her "team of seven" — a physician, nurse, spiritual caregiver, social worker, two volunteers and a bereavement counselor — all of whose names she still readily remembers, eight months after her mother's passing.

Hospice Provides Wraparound Care

In the Hospice program, emotional and spiritual support is just as critical as medical care — for the family as well as the patient. The program employs an interdisciplinary Hospice care team to provide wraparound supports for individuals and their families. What does this look like? The care team's nurse might be coordinating with the physician to manage the patient's medications for pain and symptom relief while a social worker is counseling a family member coping with the upcoming loss. At the same time, a spiritual caregiver is guiding the patient through coming to terms with the closing of their life. How is this possible? The care team works closely with the patient to develop a plan of care that meets the unique needs of each person (and their family, or chosen family).

Lisy McIntee, DeGroot's social worker, conveyed that hospice care is about providing support to ensure that people get to live and die how and where they choose.

"The earlier we receive the referral to our care, the longer we have to get to know our patients and develop that relationship. It helps us honor our patients by learning what is most important to them, where they want to be, how they want to spend their remaining time and what worries them most about end of life."

The Home Health & Hospice team encourages Vermonters to talk about hospice with their provider early on, as soon as they, or a family member, receive a terminal diagnosis. (Patients or families cannot "self-refer" to hospice; the connection must come from a medical provider, when they believe the patient is likely to pass away within six months.) An early referral also gives patients the flexibility to receive hospice care either at home, or at the McClure Miller Respite House in Colchester. □



Vision for the Future

An Update for Our Supporters



The past few years have presented enormous challenges for the health care industry. Throughout the country, hospitals, health systems, and home health agencies are struggling. Workforce challenges, increasing inflation and the ongoing impact of COVID-19 have created substantial financial challenges. The UVM Health Network – Home Health & Hospice, too, faces these challenges.

Home health and hospice reimbursement rates trail far behind the cost of care, in some cases by an extraordinary amount, and we have limited ability to cost shift. Our workforce challenges compound this issue by limiting our ability to generate revenue. Our clinical staff shortage also means that we are not able to fully meet the needs of our community.

Our mission — helping people live their fullest lives by providing high-quality, compassionate care wherever they call home — is crucial for this community. To achieve our mission, and to care for the people of our community, we must urgently address the challenges of the past few years while maintaining the highest quality care and enhancing access to services.

Recruiting and Retaining Exceptional Caregivers

Our caregivers and other staff are the heart and soul of our work. To meet the needs of our community, we must hire and retain exceptional staff and provide pathways for talented individuals to advance in their careers. We are starting FY23 in need of 22 full time equivalent staff in clinical roles, which directly translates to diminished access to home health and hospice care.

Our recruitment strategies include increasing wages as we are able, new hire and retention bonuses, and engaging staff in identifying the factors that lead them to choose Home Health & Hospice as an employer of choice.

One recent example was a switch to four 10-hour days for Hospice nurses, rather than five 8-hour days, a change our clinicians advocated for.

Our Financial Outlook

Home health and hospice agencies across the country operate on slim margins due to the rising cost of care, while reimbursement rates lag behind. Workforce challenges, as described above, apply additional pressure. We estimate that Fiscal Year '22 will end with

an 8% revenue shortfall and expenses 7% higher than budgeted. Even after community support is included, we anticipate ending our fiscal year with a negative 36% margin. This is a painful reality, and one that we need to confront diligently, urgently, and intentionally. Our margins have always been incredibly slim, meaning that we have limited opportunities to cut costs. Instead, we must focus on increasing revenue and philanthropy. Building our workforce and retaining staff is key, as is telling our story and the impact of our work.

Building the Health Care System We Deserve

In collaboration with our partners in the UVM Health Network, Home Health & Hospice will continue to be an active participant in building an integrated, academic health system to meet the needs of our community. Our collective vision is to provide outstanding care while keeping costs lower for consumers. Home Health & Hospice has a crucial role to play in increasing access to care across our community.

When neighbors are able to safely move from the hospital to their home to receive care, everybody benefits. □

Every one of us has the power to make a difference — right here in our community.

Support from our generous friends every year is crucial to achieving our vision of people thriving in healthy communities.



At UVM Health Network - Home Health & Hospice, the journey from making your gift to having a big impact is a short one. Every dollar we receive is put right to work where it is needed most:

- Making it possible for us to provide millions of dollars in charitable care every year
- Allowing us to invest in skill building, training and enhanced career pathways for our talented staff
- Enabling us to engage in innovative and collaborative partnerships to ensure we are collectively meeting the health needs of our population

Please join us with your gift today:
UVMHomeHealth.org/donations

Contact Maya Fehrs at: donate@uvmhomehealth.org to learn more about how to have your biggest impact.

In Memoriam

Home Health & Hospice thanks the friends and families who honored their loved ones by naming memorial gifts in honor of the following people who passed away between Oct. 1, 2021 and Sept. 30, 2022.

Gary E. Alberts	Theresa M. Carp	Michael W. Farrell	Louise L. Kafka	Carmen Morin	Pamela L. Shedrick
Scott A. Alderman	Glenna C. Carpenter	Barbara M. Farrington	Dustin L. Keelty	James L. Morrill	Margaret Sherman
Paul E. Allard	Felicia A. Carreon	Bruce T. Favreau	John A. Kern	Ellen S. Morris	Elizabeth C. Slayton
Jeannette M. Allard	Hilda M. Carrier	Daisy M. Field	Donald B. Kiley	Linda M. Morse	Linda M. Smith
Audrey J. Arnold	Leslie W. Chandler	Claire L. Foster	Susan L. Krasnow	Helen R. Morse	Michael R. Smith
Frank C. Baker	Joan M. Charbonneau	Lawrence G. Gadway	Carroll B. Lahue	Evelyn Moskowitz	Matthew B. Stevens
Lillian A. Baxter	Jean M. Charland	Nadine M. Galland	Bonnie L. Lajeunesse	David Murray	Robert M. Stevens
Brigid A. Beebe	Annie M. Chase	Suzanne Y. Gamache	Gisele M. Laliberte	Judith A. Murtha	Andrea F. Stitzel
Walter L. Bergeron	Carmen R. Church	Stephen H. Gelatt	Albert L. Lamson	Roy Neuer	Virginia L. Stone
Bernard W. Bessette	Peg Clark	Albert Gherardi	Theresa Larivee	Chandler D. Nims	Jeannine G. Stover
Dorothy Z. Betz	William J. Claussen	Constance M. Gill	Richard L. Lavalette	Philip H. Noel	Vaugh R. Sturtevant
Richard L. Bingham	Donald J. Clayton	Lawrence R. Gilman	Leonard J. Leene	Richard A. Normand	Gilbert R. Sujitor
Alyce F. Bixby	Lynn W. Coddington	Barbara B. Glade	Armand L. Leggett	Katherine D. Nutter	Mark D. Sullivan
Wesley R. Blair	Lori Ann Companion	Eleanor A. Goodrich	Liselotte M. Leicht	William R. O'Brien	James Szarnicki
Marcia J. Blanchard	Joan A. Conant	Terrence A. Gosselin	Gaetane M. Lemieux	Roddy O'Neil Cleary	Stanley J. Titus
Lillian M. Blanchard	Frank Corbin	Roland P. Gratton	Robert H. Liberty	Lawrence B. O'Reilly	Linda L. Tivilini
Bryce M. Bludovich	Lawrence W. Cote	Marcel R. Grunvald	Corrine M. Longe	Michael J. Page	Kimberlee A. Tokarz
Nicholas Boland	William J. Couturier	Donald S. Hall	Theresa A. Lund	George E. Passage	Martha L. Trotter
George Bolos	Francis G. Cross	Janet C. Handy	Mary J. MacCarty	Robert A. Paul	Pamela S. Tucker
Sally C. Bombard	Carole T. Cross	James P. Hanley	Gladys Macdonough	Arland A. Pike	Oneida M. Twitchell
Eric W. Bown	Dorothy D. Darling	Elaine R. Harrington	Charlotte M. Magnani	Emil Pornelos	John J. Valiquette
Lisa S. Boyle	Barbara C. DeForge	Constance M. Hart	Betty A. Mall	Brian K. Pornelos	Jean M. Viens
Barbara A. Breault	Albertine A. deGroot	Michael G. Hart	Charles Maloney	Marybeth E. Prager	Augustin J. Vila
Leonard O. Brisson	Eileen S. Dietrich	Larry J. Haskins	Francine Marshall	Janet L. Prince	Kathy A. Whittemore
Michael A. Broe	Margaret M. Donegan	Peter M. Haslam	Magalena I. May	Anthony R. Quintiliani	John J. Wills
Louise I. Brooks	Robert W. Duffy	David E. Herr	Paul I. Maynard	Ellen C. Robbins	Peter J. Wisell
Chester H. Brothers	James P. Durochua	Christine A. Heudorfer	Patrick M. McCann	William H. Rockford	Deborah C. Worthley
Carol M. Brouillard	Janet T. Dwenger	Daniel Horsford	Patricia G. McClure	Shayne R. Rooney	David A. Worthley
Patricia F. Brouwer	Gertrude B. Dwyer	Jeannette G. Hull	John P. McGovern	Edward A. Saulnier	Betty A. Wright
Robert S. Brower	Paul A. Dye	Dorothy M. Ignaszewski	Sidney B. McKeen	William F. Schramm	Lee A. Wright
Francis A. Brzoza	Paul F. Eddy	Lauren M. Irvin	Larry B. McNall	Anthony W. Schwab	Richard A. Young
Norman L. Burnett	Emily J. Ehler	A. Marlene Irwin	Wayne G. Menard	Elaine L. Segal	Robert C. Young
Leo G. Campagna	Mark T. Eldridge	Ruth A. Jerger	Diana M. Mennig Smith	Marlene J. Shappy	Walter J. Young
Thomas P. Carney	Alan R. Elrick	Donna J. Jones	Diana M. Miller	Elizabeth L. Shappy	

About Home Health & Hospice

CARE AT HOME SINCE 1906

For more than 100 years, we have provided high-quality, compassionate home health and hospice care wherever our community members call home. We support families at every age and stage of life, from pregnancy and early childhood care to adults with acute and chronic illnesses to those at the end of life. The VNA is how we started. UVM Health Network - Home Health & Hospice is who we are today.

OUR PROGRAMS

- Family and Children's Services
- Pediatric Palliative Care
- Adult Home Health
- Adult Day
- Long-Term Care
- Community Hospice
- McClure Miller Respite House

TRUSTED LOCAL CARE

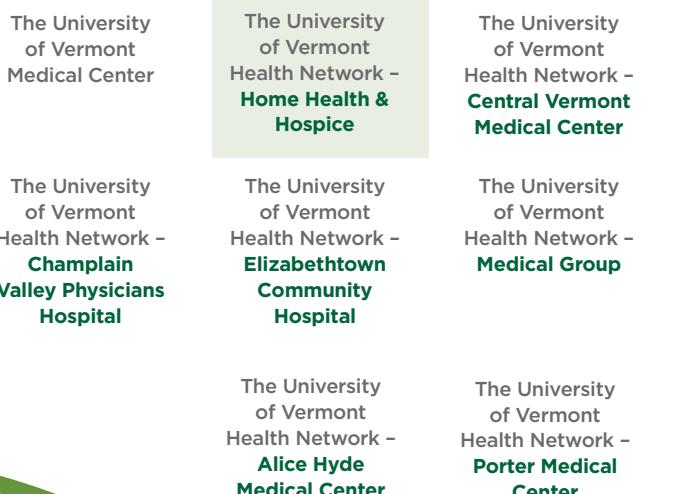
We are one of a kind. We are not-for-profit and locally led. We bring the care you need to you, wherever you call home.

As a member of The UVM Health Network, we provide trusted local care connected to a Network of expertise that benefits our patients and our people.

OUR INTEGRATED, ACADEMIC HEALTH SYSTEM

The University of Vermont Health Network is comprised of five community hospitals, an academic medical center, a multispecialty medical group and our Home Health & Hospice agency. By integrating patient care, education and research in a caring environment, we can improve people's lives. The services provided by Home Health & Hospice are a key part of the continuum of care for our patients and communities.

Together, we are working to preserve access to care for the people we serve by focusing on wellness, in addition to disease prevention and treatment, to improve the health of people across Vermont and Northern New York so our communities can thrive.



Home Health & Hospice

Friendship for Life is a publication of The University of Vermont Health Network - Home Health & Hospice.

Want to learn more about any of the programs in this issue?

Visit us online: UVMHomeHealth.org

Call us: (802) 658-1900

