

HOMECARE

connection

A PUBLICATION OF VNA & HOSPICE OF THE SOUTHWEST REGION

Reilly's Story

RAVNAH helps family face their challenges every day

Chris and Irene Jakubiak's story started with a fairy tale beginning. Experiencing love at first sight, Chris announced he would marry Irene after a chance meeting at an EMS conference they both attended. A year later, after reuniting at that very same conference, they began dating. They eventually married, and Irene gave birth to their son, Reilly, in 2006. Their story, however, took a turn in a different direction in 2008 when Reilly began exhibiting signs that something was wrong.

"Around 18 months, that's when we first noticed something was off with Reilly," Irene Jakubiak explained, bravely recounting their journey with son Reilly, who in 2013 was diagnosed with KCTD7, a condition so rare that there are only four other known cases in the United States. "We noticed a tremble in his hands, but we thought it was because he was excited."

At Reilly's two-year well-child checkup, Dr. Hogenkamp noticed that Reilly wasn't talking, and so he referred him to the Kids on the Move (KOTM) program for speech therapy services. As time progressed, however, Reilly's functions began to decline. He had his first seizure at 26 months and at 3½ to 4 years of age he became unsteady on his feet and began to choke on liquids. Irene noticed a significant decline in Reilly's condition around Christmastime

of 2010; shortly after, Rutland Area Visiting Nurse Association & Hospice (RAVNAH) began treating Reilly at home with a range of services. The KOTM program provided physical therapy (to help with his gait and balance), speech therapy (to help with communication and functional issues, such

as swallowing), and occupational therapy (to help address the tremor in his hands). In 2013 RAVNAH's Maternal-Child Health nurses began nursing services (to administer medications and monitor progress).

In June of 2014, as Reilly's condition continued to decline, pediatric high-tech nurses began caring for Reilly, to assist with the machines and equipment needed on a daily basis. RAVNAH also provides pediatric palliative care services for Reilly, the first child in Rutland County to receive such services.

There is a lot of activity with all of the therapists and nurses coming and going, but the Jakubiaks don't mind it. "Reilly enjoys his nurses and therapists, he sees it as play. He sees Mommy and Daddy all the time, so it's different faces for him to see, and the exercises and activities they do are things he likes," Irene explains. "They are totally focused on Reilly for the entire time they're here."

"They've been a tremendous support to me as well," she continued. "I can always count



(Above) Reilly with Andrea Borchlewicz, RN, his Pediatric Hi-Tech Nurse



(Left) Chris, Reilly and Irene Jakubiak pose for a family photo

"Reilly enjoys his nurses and therapists. He sees it as play. They are totally focused on Reilly for the entire time they're here."

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Bennington • Dorset • Rutland

See Reilly's Story, continued on page 5

Bennington Acquisition

Happy Fall!

Last year at this time, I wrote about plans to acquire our counterpart agency in Bennington, the Visiting Nurse Association & Hospice of Southwestern Vermont Health Care. Since then, RAVNAH and SVHC sought and received board approval, as well as a Certificate of Need from the Green Mountain Care Board, and on October 1, 2014, the two agencies officially merged.

This acquisition led to a “soul searching” of how we could maintain community support and prevent Bennington residents from feeling a disconnect with a Rutland organization. We know people are very territorial and have a strong affinity for their community. Bennington VNA & Hospice has deep community roots, having originally started as a department of the Town of Bennington, and will be celebrating 45 years of service in 2015.

To that end, on August 26, 2014, the RAVNAH Board of Directors voted to establish an umbrella organization for operational purposes. This will allow each of our agencies—RAVNAH, Dorset Nursing, and now Bennington—to maintain their own identity at each location, while streamlining operations under the newly named umbrella organization: VNA & Hospice of the Southwest Region Inc.

As you can see from the chart below, the new umbrella organization provides cohesiveness to all branches of the

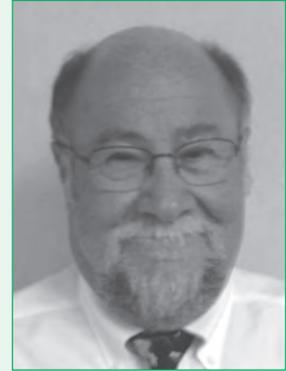
organization. Additionally, this new structure will allow each branch to maintain and expand its individual fundraising opportunities.

This name change will have no effect on our patients or staff.

We will still be doing business as the Rutland Area VNA & Hospice. Likewise, Bennington and Dorset will do business as VNA & Hospice of Southwestern Vermont and Dorset Area Visiting Nurse Association & Hospice, respectively.

I am excited to welcome our newest members to the family. We value the expertise, experience, and knowledge that SVHC’s staff and managers bring to our organization. Together, we have begun to work towards our goals of reducing the cost of care, improving the collaboration and coordination of home care, and ensuring that high-quality home health care remains available in the Bennington area.

In the coming months, we look forward to getting to know the Bennington community, expanding programs and services, and finding ways to serve the unmet needs throughout Rutland County, Dorset, and now Bennington. ☘



Ron Cioffi, CEO



Ron Cioffi Named Chamber's Business Person of the Year

Ron Cioffi, executive director and chief executive officer of Rutland Area Visiting Nurse Association & Hospice (RAVNAH), was named Rutland Region Chamber of Commerce 2014 Person of the Year at the Chamber's annual meeting on October 29, 2014.

Cioffi refused to accept the award for himself, attributing the success of the agency to the vast number of people who make up the organization. "Those of you who know me know I'm not into individual awards," said Cioffi. "I accept this on behalf of Rutland Area Visiting Nurse Association and Hospice: its board members and management team, and the 342 employees—made up of office staff, nurses, therapists, social workers, LNAs, personal care attendants, and homemakers—who made over 98,000 visits last year and who make a difference in somebody's life every day."

The award is given to a "community leader on the local, state and national level" and not usually an individual from a non-profit organization. But according to Executive Vice-President Thomas Donahue, the executive committee voted unanimously to award Cioffi the honor.

Cioffi has been with RAVNAH for nearly 40 years, and he has served as its chief executive since 1992. During the first half of the 1990s, under Cioffi's leadership, community and home care services were expanded, a strategic planning process was initiated to manage future growth, and a number of community collaborations were formed. ☪



Cioffi receives his award from Rep. Peter Welch, D-Vt.

RAVNAH's WOC Nurse Provides First-Class Care with Superior Results

RAVNAH is pleased to announce the addition of Kate Lawrence, MSN, RN, certified wound ostomy continence/ET nurse (CWOCN) to our team of providers. Kate Lawrence has a comprehensive background in wound, ostomy, tube and continence care with over 25 years of experience in acute, long-term, outpatient clinic and home care.

Studies have shown that Wound Ostomy Continence (WOC) nurses are a key factor in achieving better patient outcomes related to wound, ostomy, and continence conditions. The addition of Kate to our team allows fully comprehensive wound, ostomy, tube and continence care to continue as we strive to provide transitional and coordinated patient care services to our community and neighboring communities. Kate will collaborate with each referred patient's medical team for heightened communication, medical attention, and specific treatment.

Our goal at RAVNAH is to alleviate unnecessary worry and confusion that patients dealing with a new and unfamiliar wound or recent ostomy procedure typically encounter. Patients want to know how best to incorporate ongoing care and assistance into their lives and what they can do to aid in proper self-care and recovery. Because the nature of WOC nurse services often requires frequent medical visits over an extended period of time, it's important we provide local WOC nursing care for our patients. Not only can we provide premium care and assistance, but we can also reduce unnecessary drive time, ease concerns, and reduce costs. Reducing stress by helping patients locate and obtain wound, ostomy and continence specific products and supplies is important to us. Kate excels at helping patients return to daily life and healthy lifestyles as quickly as possible.

Kate is universally loved by her patients. The following excerpt is from a recent patient who took the time to send a full-page, typed letter singing the praises of the care he received from Kate:



Kate Lawrence, MSN, RN, CWOCN

"My reason for writing this letter is to draw your attention to Kate's wonderful and hard-working efforts to address my particular circumstances. She represents your organization very well and is someone of whom your organization should be proud. I would describe her attributes in the following manner:

Professionalism – Kate clearly is knowledgeable in the area of her expertise and demonstrates a serious attitude in seeking to solve the challenges set before her, a mark of a professional. Her daily care was outstanding.

Dedication – The difficulty associated with the placement of my colostomy was a daily challenge. She spent a good deal of time and thought in wrestling with various techniques over time to improve the wound and to lessen the need to replace the discharge bag two and sometimes three times a day. She clearly demonstrates how strongly dedicated [she is] in her work.

Positive Attitude – Kate conveys an optimism that suggests any challenge can be overcome. [P]atients already needing normal recovery from an operation might be discouraged when confronted with unusual issues developed after an operation. Thus, the optimism demonstrated by Kate certainly helps. I found it to be refreshing.

Good Sense of Humor – This is important when dealing with patients and helps set a friendlier environment under which a patient must recover. Kate was able to keep things light-hearted."

In addition to seeing RAVNAH patients, Kate provides consulting services by contract to other area health care facilities and providers. Kate also helped form the Vermont Ostomy Group, a group dedicated to providing support, education and information for the person with a bowel and bladder diversion. ☪

Dorset Nursing Association (DNA), a branch office of the Rutland Area Visiting Nurse Association & Hospice, is a not-for-profit Medicare-certified home health agency providing home health care services in the Dorset, Rupert, and Pawlet communities.



Visions Camp *Helping Young Women Strengthen Their Sense of Self-worth*



(Above) 2014 Visions Camp participants perform a special presentation on their last day of camp. (Right) Cathleen Paulin, left, and Kathleen Jensen, right, pose for a photo during the camp celebration.

Over the summer, the Dorset Nursing Association once again held the highly successful Visions Camp for adolescent girls at Christ Our Savior Church in Manchester, who generously donated the space for this year's week-long camp, which ran from July 28 to August 1.

Visions is a mentoring camp that strives to give adolescent girls many different experiences and opportunities in arts, crafts and physical activities, and exposes them to accomplished female guest speakers to help strengthen their sense of self-worth, increasing the potential to make healthy choices across the spectrum of their lives. This year, the girls participated in activities such as geocaching (navigational

techniques to hide and seek containers), created different forms of art including sand jars, t-shirt design, and necklace making, and learned about Native American culture. On the final day, the girls celebrated with a hula-hoop dance routine for friends and family.

The camp is facilitated by Kathleen Jensen, Laurie Sallisky and Cathleen Paulin. "The girls bond over learning new skills together, and they really support each other," says Jensen, who works hard to bring in successful, local women to provide meaningful workshops for the campers. "They are proud of their accomplishments achieved during the week, and it is a nice way to end the summer on a high note." ❀

Eileen Fisher Supports Visions Camp

Women's apparel company Eileen Fisher chose Dorset Nursing Association as the non-profit recipient of the company's "Share the Love" event that happened on September 20, 2014.

Customers in the Manchester, Vermont, area who shopped at Eileen Fisher's newest retail shop, located at 135 Depot Street in Manchester Center, on Saturday, September 20, 2014 helped the designer support Dorset Nursing Association's Visions Camp program, a girls' day camp that offers a place for young adolescent girls to work with successful women who provide guidance to grow and build inner strength and confidence in a positive, non-judgmental environment.

Fisher donated 10% of the proceeds from all purchases made that day at her Manchester store to help support the organization's Visions Camp program in 2015. Dorset Nursing Association, an office of VNA & Hospice of the Southwest Region (VNASWR), is a comprehensive, certified home care, hospice and community health agency serving the Dorset area residents with acute, chronic and terminal illnesses.

Sara King, CFO of VNASWR, expressed her gratitude towards



Customers were treated to appetizers and champagne while they shopped for a good cause.

Eileen Fisher for helping support Visions Camp, noting how much influence a strong female leader can have on a young woman's life.

"Eileen Fisher's commitment to running a community-focused company sends a strong and positive message to young women everywhere. Her philosophy of creating responsible, socially conscious companies makes her a role model who young women can look up to and demonstrates how far a woman entrepreneur can take her business when she has the advantage of mentors and support. That type of mentorship is exactly what our Visions Camp strives to provide for young women in the Dorset and Manchester area." ❀

StoryCorps, creator of the oral history projects heard by millions during weekly broadcasts on NPR, has chosen Rutland Area Visiting Nurse Association & Hospice (RAVNAH) to pilot a new program in Vermont, called StoryCorps Legacy. StoryCorps Legacy provides seriously ill people of all ages and their families the opportunity to record, preserve, and share their stories.

The Hospice program at RAVNAH provides care, comfort, and support for those in the final stages of life and for their families. Hospice care is available for a wide range of illnesses including end-stage lung, heart and liver disease, cancer, dementia, stroke, Alzheimer's and ALS.

Initiating the StoryCorps Legacy program at RAVNAH allows the organization to offer its hospice patients the rare experience of an uninterrupted, intentional, and intimate encounter, during which one person honors the life of another by asking them meaningful questions and sharing thoughts, feelings and memories. This

simple act is a powerful way to bring people together. According to StoryCorps, "clinical research, knowledge, and literature suggests that storytelling and reminiscence provide enormous benefits to those with advanced illness and their families, and can play an important role in comprehensive palliative [and hospice] care programs. Legacy provides a meaningful opportunity for patients, their families, and their care teams to take advantage of the power of storytelling and listening at a critical stage in life."

RAVNAH Hospice patients who wish to participate in the program are guided through the experience by Hospice Volunteers, who attended a day-long training with StoryCorps Legacy employees to learn techniques to conduct and record and facilitate the conversations. Participants receive a CD with a recording of the conversation, and they can then choose to archive their recording at the Vermont Folklife Center, share their story on RAVNAH's website, or keep their experience private. ❁

Reilly's Story, continued from page 1

on them to be there when I need them. With RAVNAH, I always have what I need when I need it." That includes times like this past spring, when Irene's grandmother fell and broke her hip and had to go into a nursing home. With Reilly being cared for at home by RAVNAH, Irene was able to look after her grandmother when she was in the nursing home. "I only missed one week the whole time she was there," Irene said. Having that extra layer of support is especially important to Irene when Chris is working his full-time job as a hydro-operator at GMP. (Chris also works per diem as an EMT at Rutland Regional Ambulance and as a volunteer fireman at the West Rutland Fire Department.) It enables her do things such as look after her grandmother, run errands, and do chores. Chris and Irene even have the occasional date night out. "It's important for them to have that time alone, to connect as a couple," Mona Rickert, one of Reilly's nurses from RAVNAH, explained.

Finding time to devote to their relationship certainly has been challenging, as Chris and Irene have been entirely focused on getting to the bottom of Reilly's health issues. They spent years performing research, going to different doctors, and trying to find similar cases that would shed some light on what they were dealing with. After years without any answers, the Jakubiaks had come to terms with the reality that they may not find an answer. Irene refused to give up, however, and looked into genome mapping—the creation of a genetic map assigning DNA fragments to chromosomes—to provide some answers. Chris was initially hesitant to undertake another lengthy process. "I felt like we were mice on a treadmill chasing a carrot," Chris explained. "It was just a never-ending treadmill of tests with no answers." Chris eventually agreed to the procedure, which was performed in April of 2012, but they had to wait a full 15 months to get any answers. In July of 2013, they learned that both Chris and Irene carried the KCTD7 gene mutation and had both passed the "active" gene on to Reilly. "We literally had a better chance of winning the lottery several times than we did of passing on the gene to Reilly. But

that's what happened," Irene explained.

"The [results of the] genome mapping meant acknowledgment that there was nothing else I could do. Until I got his true diagnosis, I couldn't stop searching," Irene explained. Now, all efforts are focused on keeping Reilly comfortable and happy. "He just loves the water, loves to swim, so we bring him up to Maine quite a bit," Chris shared.

In the past year, Reilly's condition really began to go downhill. Chris shared a video of Reilly, splashing around in a water fountain, taken just six months earlier. Today, Reilly is unable to walk, eat, or stand without assistance. Still, he has a lot to look forward to. Reilly loves watching his Disney cartoons, and the Jakubiaks are eagerly planning their fourth trip to Disney World, a favorite for the whole family. "His therapists try really hard to keep the function that he has," Irene said. "He loves the rides, and it's accessible there. So right now we're all just looking forward to having fun in Florida."

"She loves planning our Disney trips," Chris says with a smile. Irene is extremely organized in her planning, down to the last detail. Such planning takes a considerable amount of time, but it's something Irene is able to do with the support of RAVNAH's nurses and therapists. "More hands make lighter work, and they really do give [us] extra freedom," Chris explained. "This is our life, and they understand the challenges we face every day."

"Chris and I have grown close to them, and we can vent to them when we need to," Irene echoed. It's not just Reilly they provide support to, it's the whole family, and that has made a big difference in our lives." ❁



Tiffany Barber, Speech Language Pathologist, works on exercises with Reilly that aid in his communication

Special Events Bring Funds, Friends and Awareness to RAVNAH Initiatives

Each year, Rutland Area Visiting Nurse Association & Hospice holds special events within the community to raise funds and heighten awareness of its programs.

We are truly grateful to the participants, volunteer committees and individuals and businesses that contribute to the success of each of these events. We remain indebted to these hard-working individuals and generous donors, and their ongoing commitment to quality home and community-based health and hospice care throughout Rutland County.

6th Annual Bella Notte: A Beautiful Night for Giving

Hosted by Three Tomatoes Trattoria, the 6th Annual Bella Notte event raised almost \$30,000 to benefit RAVNAH's Hospice Program! Guests



enjoyed a finely prepared Italian dinner, participated in a competitive live auction, and had fun snapping pictures in the photo booth.

(Above) Cindy Seager and Ron Cioffi take advantage of the photobooth at the event. (Left) Adam and Sara King celebrate their auction item win



21st Annual Rutland Health Foundation Golf Invitational

The RHF Golf Invitational was back again, raising funds for programs of Rutland Regional Medical Center and RAVNAH. Participants were in great spirits as they enjoyed breakfast, a beautiful sunny day, and an awards luncheon following the captain and crew format tournament.

Team KSE, LLP poses for a group photo



4th Annual Dancing with the Rutland Stars

Rutland's version of the hugely popular "Dancing with the Stars" event was a sold-out hit once again—this year in record time! Tickets were a hot commodity, as the show sold out a good three weeks before the event. Over the past four years, this event has raised almost \$100,000 for RAVNAH's Kids On The Move program. Save the Date: Dancing with the Rutland Stars will be back on October 10, 2015. 🍀



(Above) DWTRS Cast, (Inset left) 2014 Winners Brent Godnick and Sam Ho, (Inset right) Fan favorites Eric Marsh, MD, and Tracy Tedesco

November is National Hospice Awareness Month

Hospice Memorial Service

The Rutland Area Visiting Nurse Association & Hospice (RAVNAH) will host their annual Tree of Remembrance Tree Lighting Ceremony and Memorial Service on Tuesday, December 9, 2014, at 6 p.m. at the Franklin Conference Center in Rutland. The Tree of Remembrance is a time for community members to gather with others to remember someone who has died. The service will include music by Trillium; reflections by RAVNAH staff, clergy and caregivers; the lighting of the Tree of Remembrance; and the honoring of those represented on the Wall of Remembrance. If you plan to attend and would like to have a name read at the service, please call 802.770.1516.

Hospice—An Opportunity to Serve

Hospice volunteering is a unique opportunity to serve community members at a potentially scary time in their lives. Becoming a volunteer gives meaning to many people in a way that paid employment sometimes cannot. RAVNAH Hospice volunteers can donate their time in several different ways, including:

- Joining Trillium, a hospice chorus formed to share their love of music by singing in small groups in a patient's home;
- Performing Reiki, a practice appreciated by hospice patients for its ability to diminish pain;
- Coordinating and facilitating Death Cafes, a public forum created to promote open and honest conversation about death;
- Educating the public about RAVNAH's Start the Conversation program, a resource available to help families discuss and make tough decisions about end-of-life care;
- Volunteering for Dinners with Love, a meal delivery service for hospice clients, consisting of restaurant-donated meals; and now
- Facilitating StoryCorps Legacy conversations between hospice patients and their family/friends. ☘



Hospice Volunteers during a recent training session with Hospice Volunteer Coordinator John Campbell (far left) and Hospice Medical Director Dr. Eisemann (far right)

2014 REMEMBRANCE ORNAMENTS

Remembrance ornaments are a special way to honor someone who has touched your life. RAVNAH's dove ornament is elegantly crafted by Danforth Pewter in Middlebury, Vermont. It measures 1 ½ inches tall and 4 ½ inches wide, is tied with a satin ribbon, and comes tucked inside a flannel pouch. Each ornament comes in a gift box with a memorial card enclosed. For more information or to place your order, please call or email Ann LaRocque at 802.770.1516 or Larocque@ravnah.org, or fill out the form below.



ORDER FORM (PLEASE PRINT CLEARLY)

Name:

Address:

City, State & Zip:

Telephone:

Total Number of Ornaments Ordered	#
Total Amount (\$15 each):	\$
Postage & Handling (\$2.25/ornament)	\$
Donation to Hospice: (optional)	\$
Total Enclosed:	\$

You can pick up your ornaments at the RAVNAH office located at 7 Albert Cree Drive, Rutland, or we can mail your ornaments by mid-December for a \$2.25 per ornament charge.

Please mail my order Will pick up at Rutland Area VNA and Hospice office

Make checks payable to RAVNAH Ornament Order and mail form and payment to: RAVNAH Hospice • PO Box 787, Rutland, VT 05702-0787

For more information, please call: 802.775.0568

ALL ORDERS MUST BE RECEIVED BY NOVEMBER 28

Welcome New Board Members!

Dan DiBattista

General Electric Plant Manager



"It's important to me to give back to the community. I've been in Rutland for five years and served on other boards. I've been interested in learning more about health care for both business and personal reasons, so I look forward to serving on the RAVNAH board. To me, home health care just makes sense. Providing health care in the person's home is more affordable for families and the health care system—and patients prefer to recover in their home." – Dan DiBattista

Win Thomas

Principal, The Richards Group



"Having witnessed firsthand the services RAVNAH provides, I am proud and happy to be a board member of RAVNAH. The position allows me to give back to the organization and strengthen RAVNAH's mission of enhancing the quality of life of all we serve through comprehensive home and community health services."

– Win Thomas

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TUNE IN TO RAVNAH'S CABLE SHOW...

HOME CARE CONNECTION With host, Harry Snyder

Don't forget to tune into RAVNAH's Cable Show – HOME CARE CONNECTION with host Harry Snyder. Program and event topics span a variety of subjects including RAVNAH's home and community health services, managing your health, prevention strategies, understanding Medicare and much, much more.

Watch on Channel 15 Mondays • 9:30 am Tuesdays • 2:00 pm Wednesdays • 7:30 pm

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Scan the QR Code to the left to "like" our Facebook page and stay updated on RAVNAH activity!



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