



## ■ Annual Report

*Compassion, comfort and care,  
when it's needed most*



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The mission of Hospice and Palliative Care of St. Lawrence Valley is to enhance the quality of life through compassionate care for people affected by advanced illness and grief.

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#### **Office Hours**

8:00 - 4:30 p.m.

Monday through Friday

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## Stories from the Road

By Dr. Sandra McCloy  
Hospice Physician

2016 is a big year of change for Hospice as the entire leadership has changed. Our new Executive Director is Ruth Fishbeck replacing Brian Gardam, who guided this organization through a huge growth in services provided and the number of patients served, as well as moving us into our beautiful building on Route 11. Our Director of Finance is Stephanie Wallace now, as Mac Shoen has also retired. Anne Karlberg has assumed the position of Director of Patient Services. And most pertinent to myself, Dr. Gary Berk is the new Medical Director of Hospice and Palliative Care of St. Lawrence Valley as of January 1, 2016. Gary brings his excellent reputation as a respected family physician in our community for over twenty-five years, as well as additional credentials in both Geriatric Medicine and Hospice and Palliative Care. Hospice is lucky to have him at the helm as we continue to grow and increase our participation in the care of the terminally ill and dying in St. Lawrence County.

As this is my last report as a Hospice Medical Director, I want to say something about what it has meant to me professionally to be the Medical Director of Hospice and Palliative Care of St. Lawrence Valley for thirty years - 1986 to 2015. My career in the practice of medicine extends from 1981, the year I became certified Family Practice and licensed in the state of New York. I was in the private practice of family medicine here from 1984 to 2014. Hospice became a part of what I did every day from 1986. I am very proud that I was a "volunteer" Medical Director for twenty of those thirty years. I always felt fortunate to have service to Hospice as part of my professional resume. Through all of these thirty years, it is my work in the field that has meant the most to me - being part of a team that meets regularly to discuss all aspects of a patient's problems, backing up the nurses with medical advice at all hours, being on-call nights and weekends for both advice and needed narcotic prescriptions, and doing the house calls. It is great to be part of a medical organization that meets such an important niche in our community by providing dignity, compassion and comfort to those in our county who choose to die in their homes with their family and friends at their bedsides. I have so many stories and experiences to savor. Thanks to everyone at Hospice from the nurses, social workers, and personal care staff to those at the "mother ship" (especially Stephanie Beaulieu who keeps me on the straight and narrow) who makes this organization go day after day. In my professional life, I can't top the miracle of using my hands to glide a newborn into this world, but, at the other end of life, I will always know that I was part of Hospice, an organization giving confidence to all those holding the hands of the dying at a bedside of St. Lawrence County. Hospice, providing house calls 24/7, 365 days a year since 1986. What a great concept!

It is the close of another year on the roads of St. Lawrence County for Hospice. This year I made 280 visits to 98 patients who resided in every nook and cranny of St. Lawrence County. I have enjoyed this job immensely. Over this last five years, I have been fulfilling the Medicare mandate that requires the Medical Director to make a "face to face" encounter every sixty days for the purpose of recertification to any hospice patient who survives the original six-month prognosis.

This year Hospice admitted 511 patients. Of those, I saw 63 new patients to me, as well as 35 from 2014. Year to year there are about ten patients who have been on our service for more than two years. In any one year, this represents 2% of the total patients served. Of the ten who survived this year, I am fairly certain four of them will die this year. At present, the other six have some extenuating circumstances, often in the psycho-social realm, that make a sign-off difficult. All of these patients meet the hospice criteria for admission in their disease category

## Stories from the Road Continued...

and they could be signed on to hospice at any time, based on the extent of disease burden they bear. Of course a six-month prognosis is fraught with human error as the human body and spirit often exceed all expectations. At Hospice, there is much objective evidence within the body of medical knowledge to help us predict, but we are not perfect. Already in New York, the Medicaid program has increased its time frame for terminal patients to twelve months. The national hospice organization is lobbying Medicare to consider this expansion as well.

I will briefly add some statistics about the patients that we have signed off. In the five years of Face to Face, that amounts to eighty-seven patients. As you might expect, this is a sick cohort and fifty of the eighty-seven have died (50% on Hospice again and 50% without Hospice). Thirty-one of these patients are alive and living in nursing homes or the community. The six patients who are the balance of the 87 are presently back on hospice services.

I want to say a few words about the ten patients who have been with us for more than two years. Of those, all meet the criteria of their diseases for hospice services. I feel three will die sometime this year. One can be signed off to Palliative services this year. Three presently live with their children. In each of these three cases, the caregiver is facing a significant medical problem that might make caregiving impossible and hence necessitate a change of residence for our patient. Hospice is uniquely equipped to help with a transition like this due to the integration of social work in our mandate. Two of these patients live alone. One is 91 and extremely limited by her disease. One has dementia complicating his hospice diagnosis and his independent living situation is tenuous. The last patient will be 104 in March. Statistically she will die this year, but I have said that for the last several years. It is difficult to sign her off and then have her die in the end without us. However, she does live in the nursing home now and is receiving excellent care. Presently she is actively losing weight again and I am keeping a watch on that.

Signing someone off hospice services is generally a heart-wrenching business. Luckily very occasionally, it is clear-cut because the patient has improved from an event that was initially thought to be a terminal one. These are often patients with heart and lung diseases, rather than dementia or cancer, as it can be particularly difficult to state prognosis even in the face of serious disease burden in the cardiac or pulmonary systems. Of course, all of those we sign off are seriously ill. Most are very frail and vulnerable and they often live with an equally frail and elderly spouse. Most have become dependent on our personal care staff for their daily bath, shave and other morning libations from

rising out of bed to being clothed, and then fed and seated in a chair for the day. Some of our patients are helped in the same way at the end of the day by our staff. Hospice is responsible to find alternative care to anyone signed off. Many go to the local home care agencies, but they lose the special consistency and reliability of our staff. The "mother ship" staff is very sensitive to our families and there are many calls to inform families if their care for the day needs to be changed or delayed. This is a courtesy that is particularly unique to our staff and our families appreciate this. Hospice also is special in the health care system in that there is 24/7 on-call in the home. No other agency has this service available in the home. And this service is due to the dedication of our hard-working, compassionate RN staff.

Those who read my reports know that I can't close without saying something about riding the roads of the county. Our county is the size of Rhode Island, you know. All the towns that I know so well now - Potsdam, Massena, Ogdensburg, Waddington, Colton, South Colton, Norwood, Norfolk, Fine, Star Lake, Cranberry Lake, Harrisville, Fowler, Gouverneur, Winthrop, Brier Hill, Hannawa Falls, Rensselaer Falls, Chase Mills, Louisville, Parishville, Brasher Falls, Helena, Canton, Hermon, Russell, Edwards, West Stockholm, Knapps Station, Oswegatchie, Pope Mills, Pyrites, North Lawrence, Antwerp, Richville, and Newton Falls. The names roll off my tongue and all are easily found on my trusty county map. Getting there and back again is part of the fun.

There are always one or two wonderful wildlife sightings. This year the most amazing was right on the edge of Route 68 between Ogdensburg and Canton. I thought at first it was a crooked stick at the side of the road, but to my amazement, it was an American Bittern, a shy marsh inhabitant that I have rarely seen. I turned around to get a better look, but the bird had slipped away. They have a call like a bullfrog and I hear them at my husband's garden in West Potsdam. Yet, there, every time I've explored down at the pond to spot one, I haven't been successful. I also enjoy watching the north country wildflower succession play out in the roadside fields as I drive by. Some favorites are trillium, lilacs in May; oxeye daisies, ragged robin, blue vetch, birdsfoot trefoil in June; Queen Anne's lace, chicory, black-eyed Susans in July; purple asters, goldenrod and touch-me-nots in August.

And, of course, I ride home each day to the music of NCPR- Tuesday to Ellen Rocco's "The Blue Note" and Friday to David Summerstein's "The Beat Authority." Happy Trails to all.

***Hospice extends its deepest thanks to Dr. Sandra McCloy for thirty years of dedication and compassionate care. Her invaluable guidance has helped to shape our organization and end of life care in St. Lawrence County.***

## Family Support Services

By Mary Jones, BSW, CT,  
Director of Family Support Services

The Family Support Services department added a new discipline to its roster; Resource Advocate! FSS welcomed Amy Peretta to the Palliative Care team and Brandy Mulvaney to the Hospice team in this new role. Amy comes to Hospice with a wealth of experience working in the mental health field connecting individuals to community resources. Brandy spent the summer interning with Hospice through the Community Health program at SUNY Potsdam. In the fall, she was hired to fill the new position of resource advocate for the Hospice program. The Resource Advocates are responsible for connecting patients to additional resources such as Medicaid, completing nursing home applications, assistance with HEAP and Meals on Wheels. These new positions makes it feasible for Social Work to carry higher case loads and concentrate on supporting the patient and family. We said good-bye to the Palliative Care Social Worker, Scott Blankenship, LCSW-R, who moved on to other opportunities.

### Caregiver Support

The second annual Caring for the Caregiver event increased the number of vendors to 23. Eighty caregivers from 10 different communities in St. Lawrence County attended the event held on June 11th. Fair-goers completed a survey and 40% of those attending were looking for education on caregiver stress and 35% indicated a need for more information on self-care. In total, 125 caregivers accessed the program in 2015. Some received one time education and others have engaged in regular attendance in the monthly Caregiver Support Group. The Caregiver Education Program and Support Group completed a full year of programs. The monthly support group starts with a mini information workshop and moves into support discussion. This monthly support group began focusing on the caregiving needs for those caring for loved ones with Alzheimer's disease and dementia. The caregiver program also offer a virtual webinar call the Longest Loss: Alzheimer's Disease and Dementia, offered through Hospice Foundation of America.

### Bereavement Services

Mary Jones and Kay DePerno presented a workshop "When Grief Comes to School: Tools for the Toolbox" to school counselors in St. Lawrence County in the fall. Thanks to grants from the Northern New York Community Foundation, Stewart Shops and a donation in memory of Christian House, counselors participating in this workshop received a complete Grief Tool Box for their school district. Under contract with St. Lawrence/Lewis BOCES, the Hospice Bereavement Services program provided support to four schools in St. Lawrence County that experienced the death of a teacher and student.

Hospice started a book club program in November. Those in attendance discussed Atul Gawande's best seller "Being Mortal." The spring 2016 book club will be discussing "Smoke Gets in Your Eyes: And Other Lessons from the Crematory" Hardcover by Caitlin Doughty.

The Grief during the Holiday series, offered monthly November – January experience record attendance. Participants learned about strategies to cope during the holidays and rituals of remembrance.

### Volunteer Services

Volunteer Coordinator, Jennifer Brailsford, continued to recruit, train and schedule volunteers. In the fall, Hospice experienced a surge in people utilizing services. With the increased number of hospice patients came a demand for more volunteers in the home. In some cases, several volunteers were visiting 3 – 4 patients each week.

### We Honor Veterans Program

On October 15, 2015 Hospice and Palliative Care was one of 10 hospices recognized during the We Honor Veterans 5th anniversary Award of Excellence. This recognition ceremony was part of the National Hospice and Palliative Care Clinical Conference in Grapevine, Texas. It was a great honor to be recognized for the services Hospice provides through the We Honor Veteran program. It should be noted that we increased the number of veteran pinning's from 45 in 2014 to over 100 in 2015.

## Families Highly Satisfied with Hospice Experience

Quality reporting to Medicare became effective in 2015 through the CAHPS Hospice survey. This survey is sent to all Hospice families following the death of their loved one. The survey uses a standardized set of questions designed to measure and assess the experiences of the hospice patients and caregivers. Based on the returned surveys, Hospice of St. Lawrence Valley (HSLV) scored well above both New York State and national results in all areas. For example, HSLV received a 92.4% favorable rating of patient care, compared to 81.9% for the state and 83.7% nationally. Families also reported they would recommend HSLV 93.4% of the time, while the state received an 85.9% favorable rating, and the national result was 85.4%. This type of feedback from families of the patients we have served earned HSLV honors as one of the top 100 agencies for which Deyta, a national company that specializes in healthcare quality measurement, administered the CAHPS surveys in 2015. This is the second time we have earned Deyta's top honors award for continuously providing the highest level of satisfaction through care as measured from the patient's point of view.

## Hospice Finances

### A Financial Snapshot of 2015 (Our Unaudited Financial Statement)

#### REVENUE

Patient Revenue	
Medicare.....	\$3,980,508
Medicaid.....	362,956
Third Party*.....	183,967

Total Patient Revenue.....	\$4,527,431
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#### Public Support & Other Income

Contributions.....	\$158,392
Bequests.....	159,163
Special Events.....	94,038
Grants.....	65,035
Other Income+.....	102
Investment Income.....	-24,472

Total Public Support & Other Income.....	\$452,258
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TOTAL OPERATING REVENUE.....	\$4,979,689
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#### EXPENSES

Personnel/Salaries.....	\$2,702,174
Employee Benefits.....	566,157
Contracts & Professional.....	85,733
Ancillary Services#.....	947,281
Administration.....	584,461
Public Relations.....	20,778
Insurance.....	42,159

TOTAL EXPENSES.....	\$4,948,743
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TOTAL REVENUE/EXPENSES.....	\$30,946
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\* Blue Cross and other insurance

+ Contracts, in-kind and miscellaneous

# Medication, oxygen and medical equipment, for example

## On the Cover...

Pictured is the Hospice Memorial Garden in June of 2015. Donors have generously named the gazebo, fountain and butterfly garden seen in the picture in honor of loved ones who are gone. Also included in the Memorial Garden is the children's garden, which boasts a giant ship play area, and the fish pond always carefully taken care of by Brian Gardam. Scattered in walkways and patios throughout are engraved paving stones with names and meaningful messages thoughtfully donated by friends and loved ones. The Memorial Garden serves as a place for quiet reflection, permanent remembrance and a gathering place for those whose lives have been touched by our care.

## Quality Assessment and Performance Improvement

By Nina Nuwer, LMSW  
Director of Quality Improvement and Information Services

Quality Assessment and Performance Improvement (QAPI) activities in 2015 continued to focus on improving the care provided to Hospice patients. Another area of focus was complying with new Medicare regulations for reporting quality measures (Hospice Item Set), and reporting of the CAHPS Hospice survey, the family evaluation of hospice care. In addition, two new performance improvement projects were started in 2014, and several projects started in 2014 were completed in 2015.

Medicare regulations requiring the reporting of a set of nine quality indicators, called the Hospice Item Set (HIS), became effective in the latter part of 2014. The process for obtaining accurate data, and reporting this data, was refined in 2015, in preparation for the impact timely reporting will have on Medicare reimbursement. These quality indicators include assessment and treatment of pain and dyspnea, bowel regimens initiated when narcotic pain medications are ordered or continued, and discussion of patient/family wishes regarding cardiopulmonary resuscitation, other life-prolonging treatments, hospitalizations and spiritual concerns. By year end, results were above 80% in all areas, but one, dyspnea screening. Review of this area indicated confusion about the question itself, and a need for further education with the nursing staff. The results for the HIS submissions will continue to be monitored in 2016 for risk areas and trends.

A Department of Health Survey in March resulted in increased auditing of patient records to better identify and address areas where patient care may be improved. Additionally, plans were developed for better education with patients and caregivers who are performing care for more complex medical issues, and better planning for those patients who have caregiving and safety concerns. In addition to education and monitoring, new policies and procedures have been developed to address these issues.

With a goal of increasing productivity, efficiency, accuracy and user satisfaction, the selection and implementation of a new electronic medical record was an area of major focus throughout the year. We ultimately decided on a new system, Brightree. Training began in July and we met our go-live date of October 1, 2015. Training on the new system continued through the last quarter of 2015, and into 2016.

We will continue our commitment to provide high quality services, and to enhance the quality of life for all patients and families who we serve.



# Palliative Care Sees the Person Beyond the Disease

By Diane Pickering, RN  
Administrative Director of Palliative Care

## What is Palliative Care?

Palliative care is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team. Here at Hospice, our team consists of our Nurse Practitioner, RN, Social Worker, Case Manager, Medical Director, Administrative Director, and clerical staff; all of whom work together to provide support to patients in St. Lawrence County. Frequently this team of professionals work together with a patient's other doctors to provide an extra layer of support.

Palliative care treats people living with serious, complex and chronic illnesses such as cancer, cardiac disease such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, Parkinson's and many more.

Palliative care is appropriate at any age and at any stage in a serious illness. Palliative care is not hospice, nor is it giving up on life. We support patients as they navigate their illness and manage symptoms. Staff are specially trained to address complex pain and symptoms, as well as in-depth communication concerning treatment options, goals and information; palliative care helps with a wide range of issues. These include medical co-management, pain control, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite, difficulty sleeping and others.

Palliative care helps patients to better understand their disease progression and assists patients in gaining the strength to carry on with daily life. Patients are more comfortable discussing alternatives, making decisions and establishing their goals for health care. It also helps support family caregivers.

People receiving palliative care report better quality of life, ability to function, understanding of their options and feeling back in control of their lives.

## The Growth of Palliative Care

In the last 15 years, the field of palliative care has experienced exponential growth. It is a rapidly rising trend and we are no exception! Our service has more than doubled since we began in 2014. The palliative care team has done more

than 1100 visits in 2015. The patient's insurance is billed for these services; however, approximately 30% are non-covered services as most insurances do not reimburse our RN and Case Manager services.

2015 was a busy year as we developed our palliative care services, expanded our team and continued to educate providers and the community about the benefits of palliative care. We are experts in supportive care and hope to reach more patients in 2016. The need continues to grow.

Palliative care is not hospice end of life care, rather it is a specialty intended to support people with serious/chronic illness. Palliative care sees the person beyond the disease. It represents a paradigm shift in health care delivery and it is our sincere hope that we can assist in caring for those people currently struggling with chronic illness throughout St. Lawrence County.

# Patient Care Services

By Anne Karlberg, RN  
Director of Patient Services

In 2015 Hospice broke a record, reaching and sustaining a census (average number of patients each day) of 100 or more on eleven occasions, and providing more days of patient care than ever before. The dedication of Hospice staff was evident as they worked long hours and provided needed support and encouragement to one another to ensure all patients received the highest quality of care.

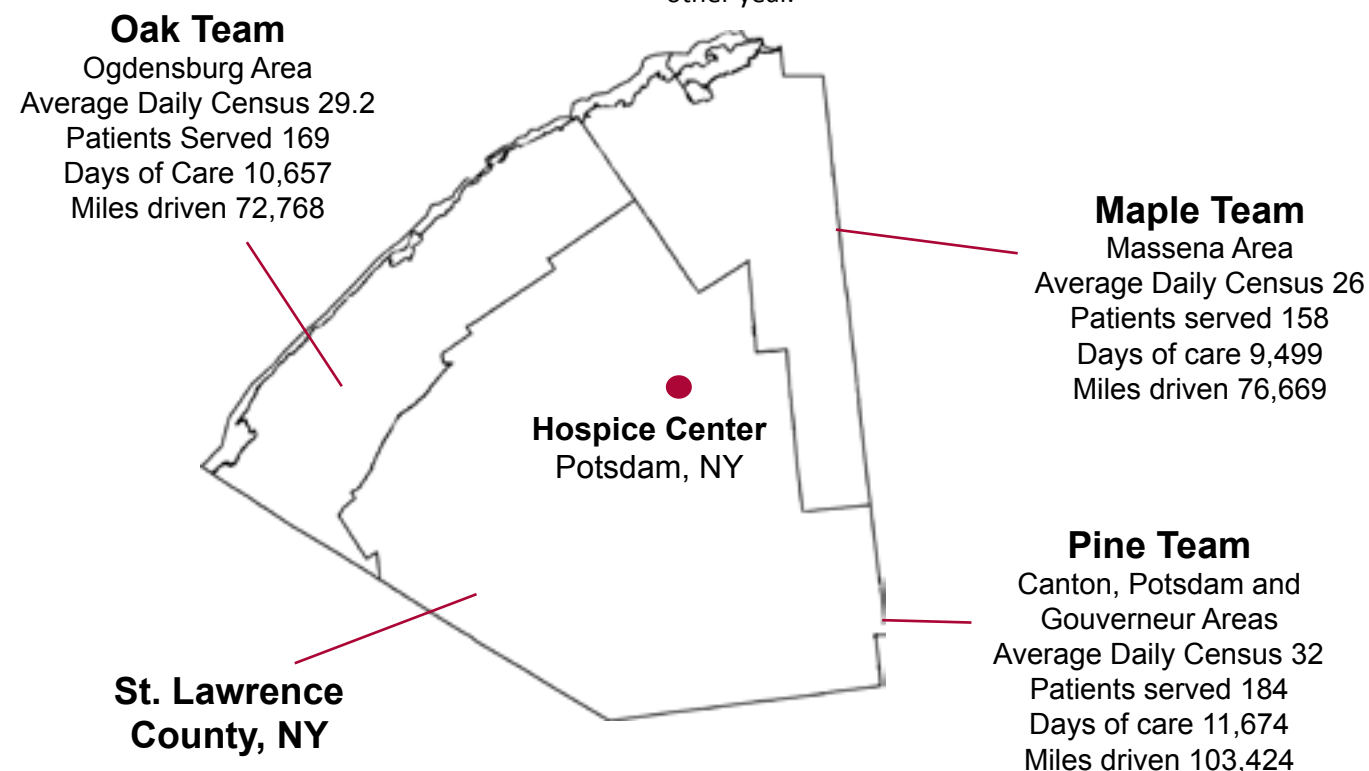
With the increase in number of patients served, several new staff members joined the hospice team in 2015. Shirley Dashnaw, RN has joined our Oak Team as a primary nurse. Warren Franklin, RN, is a full time on-call nurse for the Maple Team. We have also added two full time staff who will float to fill various staffing needs on all three of our teams. Christina Elwyn, RN, and Samantha Thaller, RN, will be working with patients throughout St. Lawrence County. New direct care staff this year include Stephanie Hooper, LPN, Danielle House, LPN, Rachael Simons, LPN, Bobbi Jenne, HHA and Cayleigh Murray, HHA.

Another big change in 2015 was the implementation of the Brightree software. The nurses along with the direct care staff now document on iPads. This has allowed our direct care staff, the LPNs and HHAs who travel around the county providing wonderful personal care to our patients, to be able to document immediately in the patients' charts. This has greatly improved the communication of patients' needs among staff and has helped improve quality of care.

# Hospice Care Around the County

Hospice care is a mobile service, with staff and volunteers driving to visit patients in their homes, nursing homes or hospitals. Within our service area of St. Lawrence County, care is provided by three teams: Oak, Maple and Pine, with all staff using the Hospice Center in Potsdam as their base.

The Pine team serves the largest geographic portion of the county and Maple, the smallest. In 2015, the Pine team also served the greatest number of patients. Hospice staff logged more than 252,861 miles in 2015 to provide care to 511 patients. In total, staff provided 31,830 days of patient care - far surpassing care provided in any other year.



# Development and Community Relations

By Kellie Hitchman  
Director of Development and Community Relations

The sentiment echoed throughout this edition of the Annual Report illustrates a record breaking year. Having cared for 100 patients or more on several occasions, providing more days of patient care than ever before and experiencing increased attendance at many of our community programs, you can imagine that made for some extremely busy days for our staff and volunteers. While they executed each visit with the patients and their families with dedication, compassion and skill, there are many heroes the patients will never meet - Hospice's many faithful supporters. Thanks to the generous support of our donors, patients and their families have access to extra nursing and personal care visits when needed, palliative care, expensive medications, bereavement and spiritual care and community programs to help educate family members caring for a loved one. It is this support which allows Hospice to provide care beyond what is covered by insurance.

Whether you chose to make a gift to the Annual Appeal or in memory of a loved one, attended one of our Tastes brunches, pledged support during the annual Radiothon, courageously swam a mile for Hospice, or attended one of the many special events organized by dedicated community members such as the Community Bank Golf Tournament, the Hospice Motorcycle Run, the Bob Law Memorial Golf Tournament, Parishville AMVETS Ladies Auxiliary Walk/Run and many other activities, you had a part in each of the 31,830 days of care we provided.

It is truly humbling to witness the amount of community support Hospice is shown throughout the year. This support serves as motivation for our staff to continue providing excellent care. Indeed, "it takes a village" and we are privileged to provide these important services in the community with your continued generous support.

Thank you all!

