

Quilt News

The NAMES Project,
New York Capital Region

Winter 2008



Names Project New York
Capital Region Chapter

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A Panel Maker's Story of Love

by Sr. Mary Ann LoGiudice



I am writing this article as I sit absorbing the beauty of the mountains while on retreat at Weston Priory in Vermont. This is a place of peace and solitude, and my daughter Barbara spent time with me here at the end of retreat each year. It was a sacred place for both of us.

I was able to adopt Barbara when she was three years old through an amazing series of

events. I will always be grateful to my religious community, the Sisters of Mercy, for granting me permission to adopt her, and to Bishop Hubbard, for his affirmation and support.

Barbara lived at Farano Center for Children, a program of Community Maternity Services and Catholic Charities of the Albany Roman Catholic diocese. Farano was the first licensed residence for children with HIV in New York State. Barbara arrived there early in 1988, and her best friend Amanda came a couple of months later. They were happy, vivacious, wonderful little girls. They were truly soul mates, and spent a lot of time together. As luck would have it, a single woman, June, adopted Amanda and they lived a few short blocks from us, allowing their friendship to grow and flourish.

When Barbara arrived at Farano, her mother was very ill from complications from AIDS. Barbara had been very well loved and nurtured by her mother. A few weeks after Barbara arrived, her mother died. This was a very difficult time for Barbara, as she tried to figure it out in her three-year-old mind. She deeply grieved the loss of her birthmother.

About a year later, I brought her to view panels from the AIDS Quilt at the convention center. She had the opportunity to go off with a volunteer and draw her feelings about the loss of her mom. This exercise was helpful to her, and she told me she wanted to make a quilt panel for her mother. I asked Sister Mary Grace, a staff person at Farano, to assist her in making the panel. Barbara designed the panel herself, and the two of them created it. The panel has a big bunch of colorful flowers, around which Barbara wrote, in her child's hand, "To Mom, Don't Worry, Be Happy, Love, Barb." The message is beautiful in its simplicity. We kept the panel for a while so she could show all our family and friends. It was very therapeutic for her to show the panel and talk about her "mommy in heaven", as she referred to her birthmother. We then brought the panel to closing ceremonies and it was dedicated with many of our family and friends present. The experience was emotional and healing for Barbara and me.

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AIDSWalk 2007 Was a Great Success!

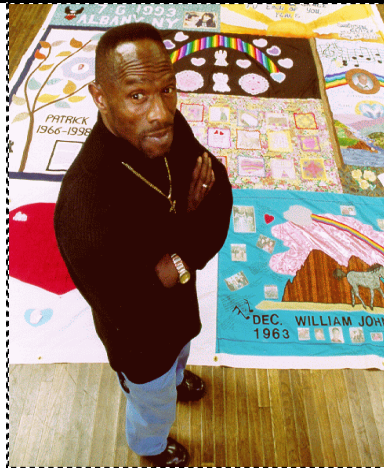
by David Jennings, Board Secretary

As the AIDS Walk Coordinator for our NAMES Project Chapter, I want to start out by thanking all of you that helped to make this year's AIDSWalk such a HUGE success! Families, people of all ages, students, professionals—community members from all around the Capital Region came together to help raise much needed funds for AIDS prevention and care. More than 100 teams representing faith communities, schools, fraternal and governmental organizations, and businesses from throughout the greater Capital District region all participated again this year. All totaled, over 2,000 Walkers raised over \$200,000 in support of 30 local AIDS service organizations that provide food, emergency assistance, prevention services and day to day support to area families living with the disease.

People literally took a "Step in the Right Direction." AIDS Walk offers a unique way to respond to this epidemic. AIDS is still an important concern in our local community and the nation. We now have more people living with HIV/AIDS in the Capital Region than ever before. HIV infection is on the rise again, with persons under the age of 25 showing the highest percentages of new infections. Each year, an estimated 42,000 new HIV infections occur in the United States. Approximately 50% of people living with HIV/AIDS are not in regular HIV care, and as many as one fourth of those infected with HIV do not even know they are positive, so it is important for people to get the facts and get tested.

The Opening Ceremony at AIDS Walk was a very moving experience. Perry Junjulas spoke as a person living with HIV/AIDS and to the importance of keeping up the fight against AIDS. In addition, there was the presentation of an AIDS Quilt made in memory of our own past board member, Mark Hayes. Mark died on April 3, 2007. His friends, family, and life partner, Bill Keyes, created a magnificent panel in his memory. How fitting it was that the first time Mark's panel was displayed was in front of the very community he fought so much for.

Next year, the 12th Annual AIDSWalk is scheduled for September 28th, so mark your 2008 calendars and join us at the Walk to "Take a Step in the Right direction!"



The AIDS Community Mourns the Loss of One of Their Own

By Rev. Jill Farnham,
Board Treasurer

Julian Dewitt Bain was born in New York City on August 31, 1944 and died in Albany on October 10, 2007. In those 63 years, Julian found a way to really make a difference. Julian touched the lives of children, people with addictions, and people living with HIV/AIDS. He first found his own recovery and spirituality, and then worked to help other people.

He worked tirelessly to bring the message of hope and empowerment to people throughout the Capital Region and around the world. When Julian had the opportunity to travel to South Africa, he learned the power of advocacy particularly through the Quilt.

Julian served as a member of the Board of the NAMES Project Capital Region Chapter for six years, and took the Quilt with him whenever he spoke. His message was strengthened by his experience as a person living with HIV/AIDS, and he was proud to be able to share his story. The work our Chapter did with HIV prevention education in the addiction centers could not have been as successful if it weren't for Julian's unique speaking style and his devotion to the cause.

The many parts of Julian's life came together through his involvement in his church, the Leadership Training Institute, the NAMES Project, the Whitney M. Young Health Center. He was also involved with Community Hospice, the AIDS Global Advocacy, the Ryan White HIV Network, Capital Region AIDS Walk, and frequent advocacy efforts at the New York State Legislature and the US Congress.

We have been blessed by Julian's gifts and his courage. He left a legacy that crosses generations and cultures.

A Panel Maker's Story

Continued from pg 1:

The NAMES Project tried to bring the panel to Albany each year, and it was very special for us to go and view it again.

Barbara died in August of 1993 when she was almost nine years old. Amanda died in September of that same year. Needless to say, I was devastated by this loss. It took me many years to grieve; but now, most of the time, I can remember Barbara with joy and gratitude for having had the wonderful opportunity to be her mother. She was, and will always be, the greatest gift in my life. I think her message to me would be the same as the message she sent her birth mother in her quilt panel: "Mom, don't worry, be happy. Love, Barb." Her love continues to reach me and I do not worry about her because I know she is with her birthmother until the day all of us live together where there is no pain, forever happy at last.

A few years after Barbara and Amanda died, I decided I would like to make a panel for them. With Mary Lou's assistance I figured out how to do it. By this time, Amanda's mom had died from complications from diabetes, so a few of my nieces and friends came together to make the panel. It took us a long time, but when it was done, it was very reflective of each of their personalities. Barbara's has her favorite Goofy sweatshirt, and Amanda's her Minnie Mouse costume; each their favorite Disney characters. The girls had been to Disney together; one of many cherished rites of childhood the disease did not steal from them or from those of us who loved watching them grow. Both panels were sewn together, which was truly appropriate, since

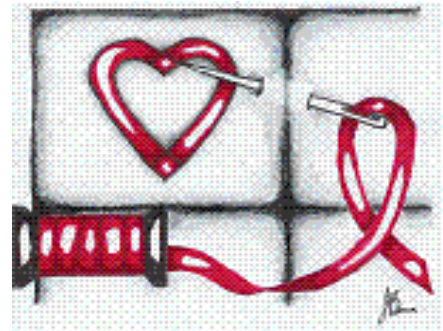
Barbara and Amanda were inseparable in life.

The dedication ceremony was both gratifying and emotional; an experience that I will never forget. As I read what I had written about Barbara, I was filled with love and pride. A good friend did the same for Amanda. That their panels are a part of the AIDS Quilt gives me great satisfaction and delight. They are used in classrooms to educate students about AIDS, and to help increase awareness of this disease. The panels are now part of an impressive 12x12 creation, and the local NAMES Project Chapter continues to bring them to Albany each year. I always go to see them; often with family. I now have grand nieces and nephews who know all about Barbara, even though they were all born after she died. I plan to bring them to view the panels with me someday as they get old enough.

I am comforted each time I view these panels and reflect upon how both Barbara and Amanda enriched and changed my life forever. Each panel tells a story, which unfolds for those who take the time to view the panels and learn a little about the people whose lives have been taken by this devastating disease. The legacy of the Quilt ensures those lives will never be forgotten. The panels inspire me to continue fighting for services for families affected by AIDS until there's a cure. I am proud to do this through CMS' Farano Families in Transition program. I am also proud to serve on the Board of the New York Capital Region Chapter of the NAMES Project, where I can continue to advocate for those still living with HIV/AIDS and help preserve the rare gift the Quilt gives to those left behind.

Editor's Note:

Sr. Mary Ann has always held a special place in the hearts of our Chapter's Board since she dedicated Barbara and Amanda's panels at our first Quilt display ten years ago. We were very fortunate that she agreed to join our Board of Directors in 2007. Although each and every one of the 96 Quilt panels that have been dedicated to our Chapter over the past 10 years are beautiful and unique in their own special way, Barbara and Amanda's panels have had the greatest impact on the young people who visit our displays. Through the magic of the Quilt, these little girls continue to touch the hearts and minds of all those who view their panels.



If you or someone you know is interested in making a panel for the AIDS Memorial Quilt, the NAMES project has a variety of resources and support personnel to help you. You don't have to know how to sew; you just need to have in your hands and hearts the longing to remember.

Please check our website for information on how to make a panel: www.AIDSQuiltNY.org or by phone: (518) 465-0595. Thank you.

The NY Capital Region Chapter Celebrates Our 10th Anniversary.

by Darin Hollenbeck

The idea for creating a chapter of the NAMES Project Foundation in our area came after a group of individuals from the community got together to volunteer at the 1996 display of the AIDS Memorial Quilt in Washington, DC. The three day display was an empowering and moving experience for everyone involved. After returning home, the volunteers entertained the idea of creating a chapter here in Albany. An exploratory committee revealed that there was a need in the Capital Region to have the Quilt in our communities. To use the Quilt as an education tool against the spread of the disease, and to raise awareness of the AIDS pandemic would have a tremendous impact.

A steering committee was formed to establish a work plan and timeline for forming the Chapter, then we were off and running. In 1997, the name for the Chapter was chosen and the steering committee filed the appropriate paper work with the NAMES Project Foundation. For the first three years, the "New York Capital Region Chapter" operated under the umbrella of the Council of Community Services. In 2000, the chapter was incorporated and established its own 501©3 as a non-profit community-based organization with an official Board of Directors.

Our Chapter's on-going mission is to illustrate the enormity of the AIDS epidemic by showing the humanity behind the statistics through the AIDS Memorial Quilt. By using the Quilt as an artistic and humanitarian response to the AIDS epidemic, we place great emphasis on increasing public awareness of AIDS in and around our community, emphasizing that the crisis is not over, educating about HIV prevention in the Capital Region, and empowering survivors to remember their loved ones lost to AIDS by creating a meaningful remembrance through individual panels that comprises the AIDS Memorial Quilt.

Our first large display of the AIDS Memorial Quilt was at the NYS Museum in 1998. This was a huge undertaking for such a young chapter; but with a lot of hard work from the Board of Directors and local HIV/AIDS community, the display was a success! Every year since then, the NY Capital Region of the NAMES Project has partnered with the NYS Dept. of Health; AIDS Institute to conduct a large Quilt display around World AIDS Day.

Over the past decade, over 15,000 middle school and high school students have visited our displays and witnessed the power of the AIDS Memorial Quilt while learning how to protect themselves against HIV infection. There have been thousands of visitors to our displays and a countless number of volunteers from the community have helped us to make the displays possible. Each year, our Chapter provides panels of the AIDS Memorial Quilt to dozens of local schools, universities, community based organizations, and places of worship. This has allowed thousands of individuals to view the Quilt, and to "Remember Their NAMES".

To commemorate our ten years of accomplishments, the Chapter held a gala fund raiser on World AIDS Day at the Albany Institute of History and Art. The event celebrated the work of many individuals who have helped our chapter by volunteering your time, providing financial support, and participating in panel making and other activities in support of the NAMES Project's mission. The visionary behind the AIDS Memorial Quilt and the founder of the NAMES Project Foundation, Cleve Jones, was in attendance and spoke about his life's work with the Quilt.

A few previous members of our Board of Directors were present at the gala: Daniel Tietz, Dave Putnam, Debbie DeRosalia, Pat Gogol, and Lenny Hoffman. The Chapter also honored the memory of five Board Members who have passed away with AIDS by lighting a candle in their name: Bonnie Tillman, Jimmy Mack, Fr. John Lysogorski, Mark Hayes, and Julian Bain.

The gala also provided a unique opportunity for our Chapter to present this year's Father John Lysogorski Community Hero Award. Perry Junjulas was honored for his years of dedication, service, and commitment to the AIDS community in the Capital Region. (For more on the Fr. John Lysogorski Hero award and the 2007 recipient, see Steve O'Neill's article on pg 5.)

Our little grassroots Chapter has been through a lot over the past ten years. We have seen Board members come and go; benefited from all their experiences and grew from their influence. We have survived the NAMES Project Foundation's move from San Francisco to Atlanta, and the many changes that came along with that. We continue to service the communities we live in, and continue to be blessed by all the wonderful people we come in contact with because of the AIDS Quilt. Our accomplishments are great, but would not have been possible without the care and support from our community. Thank you!

Quilt E-News

The New York Capital Region Chapter of the NAMES Project is changing the way we do our newsletters. We are going electronic with our newsletter and other notices. This will save our little non-profit organization a lot of money; while at the same time, allow us to increase the quality of our publications.

Our chapter would love to continue keeping you informed of what we are up to, and where we will be displaying the AIDS Quilt. Please log on to our website: AIDSQuiltNY.org and follow the instructions to enter your information in the link provided. Rest assured, your email will NEVER be shared with any other organization and is only for the sole purposes of our chapter. Thank you!

The 10th Annual Display of the AIDS Quilt in Albany



The 2007 World AIDS Day display of AIDS Memorial Quilt was held November 26th through the 30th at the Empire State Plaza's Convention Center. There were over 520 individual Quilt panels on display for the week long event.

World AIDS Day is a day of remembrance and a day to raise awareness of the HIV/AIDS epidemic in our state, our nation, and throughout the world. New York's HIV data shows that young people are becoming infected with HIV at an increasing rate. Every hour in the U.S.

two young adults under the age of 25 become infected with the virus. This alarming fact calls for our persistent attention and intervention. Our Chapter's annual World AIDS Day display provides an opportunity for members of the community, especially students, to be more aware of HIV/AIDS; and to help build on New York's commitment to providing prevention, treatment, and supportive services to persons who are infected or affected by HIV/AIDS.

This year, we saw an unprecedented number of Middle School and High School students from local schools attend the display. All told there were 2,218 students who viewed the Quilt and took part in peer-led educational sessions on HIV prevention! As in previous years, the educational sessions began with an orientation where they learned about HIV/AIDS and the history of the AIDS Memorial Quilt. The students then viewed the display. They were instructed to find a specific Quilt panel and answer some written questions about that panel. After viewing the Quilt, they returned to the class room for a debriefing where they discussed their experience. During the debriefing session, they were introduced to a person living with HIV/AIDS and were able to ask questions of the speaker about his/her life experiences.

The 2007 World AIDS Day display of AIDS Memorial Quilt was a tremendous success. The NAMES Project would like to thank the New York State Department of Health, the peer educators, and the PLWHA guest speakers who worked so hard to make the event so wonderful. Believe it or not, plans for the 2008 display are already in motion. We hope to see you then!

The Father John Lysogorski Community Hero Award

By Steve O'Neill, Board President

In 2003 we lost one of our board members, and the entire community lost a great friend: Father John Lysogorski. To help keep his memory alive, our NAMES Project Chapter began the Fr. John Lysogorski Community Hero Award in 2004. This annual award is intended to honor a member of our community who exemplifies the same qualities that Fr. John had with regards to servicing the HIV/AIDS community in the NY Capital Region.

Past recipients of this award are: Dr. Peter Pilliaro, Debbie DeRosalia, and Mark Hayes. The 2007 award recipient possesses Fr. John's unique qualities to a fault. Perry Junjulas began working at the Albany Damien Center in 1998 as one of only two paid staff. Under his leadership, the center moved to its present location on S. Lake Avenue: a safe, comfortable, homelike setting on the edge of Albany's Washington Park.

With Perry as Executive Director, the Albany Damien Center has flourished and continues to expand its many services. There are now 16 employees running many vital programs covering nutrition, support groups, pet care, counseling, and communal meal... just to mention a few. In addition to all his E.D. duties, you can find Perry driving people to doctor's appointments, BBQing in the Center's backyard, or sitting with someone in distress just listening and being supportive. For Perry, as with Fr. John, the needs of the community always come first. Those needs will be filled by whatever means necessary regardless of how many hours, days, or weeks it may take. Nothing is impossible if you refuse to give up. We are honored and blessed to have Perry Junjulas advocating for those living with HIV/AIDS in our community.

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