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REAL HIV EDUCATION

by ANDY GOODBAND

The REAL School is an alternative school in Windham. Carla Turner is a teacher at the school who has pushed HIV awareness and education into the forefront. This article is written from a conversation I had with Carla and the essays her students shared.

Carla Turner believes that learning happens through personalized experience. She teaches a class called "integrated media production" for high school aged kids. While the students become involved with their production, they end up learning a lot about the subject and themselves in the process.

Until a few years ago, sex education at the REAL School consisted primarily of an "annual condom demonstration" conducted by a person from Planned Parenthood. After, the staff had a special in-service workshop about HIV/AIDS, including a discussion with a person with the virus. Carla saw a need for more education for her students.

She says, "Because of the economic and cultural deprived situation of many students who attend the REAL School, there is a lot of inherent homophobia." The general belief about HIV was that it only happens to gays and drug users. Carla decided that the topic of HIV in Maine would become the focus of her media class. This was a way to change the students' behavior and create a positive peer educational experience. "The less directed these projects are," she says, "the more likely the kids are getting the message."

Since 1992, her classes have produced several projects about HIV. "Real Kids, Real Sex" was their first video project. Next was a photographic exhibit renamed "The Vincent Boulanger Memorial Exhibit: Fight HIV, Not People With It". This project has achieved national recognition. This year the class produced a public service announcement for several TV stations, and another video. "The Realities of HIV" is a compilation of ten interviews with persons living with HIV. This spring, the class received an America's Future Award for their accomplishments in HIV awareness and education.

People with HIV are no longer strangers to the REAL School. Several people have been "adopted" by the students, visiting weekly to help with photography or just to talk. Some people, like Vincent before his death, have spent a great deal of time with the kids. Carla says, "It has been great to have them around. The personal contact is what makes such a difference for these kids."

For an essay assignment, Carla Turner's students wrote about their experiences learning about HIV/AIDS. The following are a few statements taken from their essays.

"I thought people who had the disease were just homosexuals, they were the only ones who could get it." - a female student.

"The way I feel about working with people with HIV is that they are just like ordinary people with feelings and opinions." - a male student.

"It also teaches that AIDS is not a gay thing or a drug thing; it's just an AIDS thing." - a male student.

"I thought I'd be able to tell that they were HIV positive. Meeting these people and hearing their stories made me think how anyone can get HIV." - a female student.

"At first, I was kind of nervous, but after getting to know them, I see how they feel and how they're going on with their lives." - a female student.

"Now that I'm pretty educated in the HIV area, when people don't know, or if they've got a question, I can fill them in on HIV and AIDS." - a male student.

If you are interested to know more about the REAL School or would like to get involved, contact Carla Turner c/o The Real School, 55 High Street, Windham, ME 04062, or telephone (207) 892-4462.
This is our third issue of IN THE AFFIRMATIVE. As always, we've tried to cover a diverse group of stories, and with this issue, we feel we've hit the jackpot.

Andy Goodband, a force to be reckoned with, has contributed, not one, but three excellent stories concerning our community. His stories on the Buddy Program and The REAL School are written from the very personal points of view of the people he interviewed. Particularly moving is the sharing that Thom and Ellen let us in on concerning their involvement in The Buddy Program. His story on the Maine Community AIDS Project's survey is really just the tip of the iceberg on the subject, which will become even more prominent in the coming months as the results are viewed by more and more people.

Having joined us in print for our second issue, Deborah Shields (she's the Executive Director of The AIDS Project, you know) concludes her two-part article on legal documents persons with HIV/AIDS should be thinking about having executed. We are thrilled to have her expertise to share with you, as well as her wry sense of humor. She'll be a regular contributor to these pages.

We try very hard not to assume that everyone knows everything we know about what's available in the community, so Chris Behan's article on Peabody House is an example of our effort to reach out and broaden the knowledge of our readers.

Charlie Wynott and Jon Piefer's story on the still evolving project named Pets Are Wonderful Support (PAWS) reminds us of the touching and healing bonds we make with our pets and the needs of both pets and owners for support.

We've tried to include a very interesting mix of stories and ideas to inform our readers of the many projects and programs available to us in Maine's HIV/AIDS community. It takes a lot of pieces to make the whole of services and support for persons with HIV/AIDS.

Finally, we dedicate this issue to the life and work of John Preston, who died recently from AIDS. He was a prolific writer and activist and he leaves us all with a better understanding of our world.

- Mike Martin

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- at the onset of opportunistic infections
- if you have relationship difficulties
- when you need someone to understand
- at other times of stress

Call your Case Manager at The AIDS Project at 774-6877 in Portland or 783-4301 in Lewiston, or Brian Kendall at 934-0216, or Linda Jipson at 828-8002
PAWS
by Charlie Wynott and Jon Piefer

PETS ARE WONDERFUL SUPPORT

Nadia Sutton co-founded PAWS/LA five years ago after a friend hospitalized with AIDS returned home to find his cats had been given away.

"He was heartbroken," she says, "It's great to get the wonderful hospital care and medication, but what people need is quality of life and love. If you're sick with AIDS, you can do all the doctors in the world, but if you don't have quality of life...why stick around? And the animal is the last remaining bastion of unconditional love."

Charlie Wynott and Jon Piefer, founders of the Maine chapter of PAWS/MAINE, agree.

"PAWS helps persons with AIDS keep their dignity and power," they say. "Too many lose their homes, their jobs, their friends. PAWS has a passion for persons with AIDS and their animals."

Found to have AIDS in 1985, Bill Enos doesn't get out since his health began to slow him down this year. It's been a year in which he lost his job as a dishwasher and now he stretches a social security check to its limits. He had to sell most of his belongings and move to a smaller place. And then, his friends stopped calling, stopped dropping by.

"These are my friends now," says Enos, 28, petting a Himalayan kitten sleeping on his lap and Dusty, a cocker spaniel, at his side. "And Doug is my friend, a good friend. I look forward to his visits."

Doug Heaney, 30, is a volunteer with Pets Are Wonderful Support, or PAWS/LA in California, a non-profit group that assists people with HIV/AIDS in taking care of their pets. Heaney has AIDS, but is well enough to drive to Enos' home every two weeks to drop off pet food, take Dusty out for some exercise, and play with the kitten and the

(more on page 7)
The Buddy Program is a service of Merrymeeting AIDS Support Services in Brunswick. Individuals living with HIV/AIDS are paired with a trained volunteer who provides emotional support and friendship on an ongoing basis. The relationship may last a year or longer.

The stories that follow are from one pair currently in the program. I sat down with the two participants individually and asked them to tell me about the experience of being in the Buddy Program from their own perspectives.

The story below is from Thom and the story on the opposite page is from his "Buddy" Ellen.

Thom returned to Maine in January of 1990. The death of his spouse in 1985 and his subsequent diagnosis brought him back to Maine to be close to his family.

For a year and a half he struggled to fill the gaps in support and resources necessary to put his life back together again. He utilized The AIDS Project to help get through some of the bureaucratic obstacles necessary for living assistance. He also went to The PWA Coalition to make use of the support programs offered there. Every service that was available he grasped at to help him improve the quality of his life.

Still, he was missing some more constant source of support. He was searching for something that would really provide a direct impact on his day-to-day living. At that point, Thom got involved with the Buddy Program.

It was two and half years ago that Thom met with someone from the Buddy Program to complete the initial intake interview and to evaluate his specific needs. The very next day a woman called to introduce herself as his Buddy.

The first month for Thom and Ellen, his new Buddy, was a trial period to see how they would gel along. "If I had any expectations of what a Buddy should be, it was not what Ellen was," Thom said. "We shared some common hobbies and both of us loved the beach, but beyond that, I could not see where the real connection was."

"By the forth or fifth month, we knew that we would be friends, though." The friendship was finally beginning to evolve. "During the rest of that year, Ellen was the one that held me up...I realize now that it was about a give and take, and just spending time together."

As for Thom's family, he says, "They are as supportive as they can be. I couldn't ask for more, still, Ellen has a special role. She takes the pressure off my family. I unload a lot with her." Talking about tests results or the pain associated with Thom's neuropathy are not always easy topics of discussion with his family. He says, "Ellen and I talk everyday...we talk about everything."

Ellen now teaches at a technical college. Her schedule has become more demanding than it used to be. Thom helps her with computer projects for her work. "She assigns me projects to do for her...I think she does it intentionally to challenge and stimulate my mind," Thom says, "And keep me on my toes."

"We love to discuss current issues, and yes, occasionally get into heated discussions as well. I think it is healthy to keep your mind active." "All the agencies that I've dealt with have helped me at different times, but the Buddy Program has made a difference in my day-to-day life." Thom says.

Thom and Ellen have shared the ups and downs throughout the two and a half that they have known each other, but there is no doubt that they have come through stronger for it. Thom says, "It has given me a lot of pleasure to see Ellen learning so much about HIV/AIDS in the last couple of years. She has gained a new perspective of the daily struggles that come along with this disease."

Thom stated that the main reason he decided to do this article was that he had previously read an article in IN THE AFFIRMATIVE by John Alexander that he felt for the first time really represented the way he felt about a person's right to health and living choices. Thom says, "It is time that more people know there are choices you can make for yourself, and that the doctors' idea of quality of life may not be the same as your own. The system can often work to take away your feeling of power. My goal is to maintain a sense of power over my own life."

Thom suggests that you should evaluate the services available to you, and then ask what can they do for you. "That's where the Buddy Program has worked for me. Ellen doesn't always have the answers, but she is always there to listen."

Ellen's story starts on the opposite page.
A difficult divorce after a 20 year marriage, separation from her children, the sudden death of her father, and her mother's illness brought harsh realities to Ellen's life. She says, "I was devastated. I didn't know what to do with my life." Highly educated in medicine and immunology earlier in life, she decided to return to academia. During this turmoil, Ellen moved back to Maine to pick up the pieces and to get control of her life.

Motivated by a friend’s experience on the AIDS Hotline, Ellen decided to look into a volunteer opportunity. It happened that her inquiry was just three days before the next Buddy Training Program in Brunswick. She contacted MASS director Brian Allen and signed up.

At the first session, Ellen listened to the "noble" reasons why others were involved in the program. When her turn came, she replied, "I'm not sure why I am here. I'm not sure that I should be here. I think I have something to give and I am looking to get something out of this experience as well." Ellen had a great knowledge of the disease process of HIV/AIDS from her immunological background, but she knew nothing of the people who were living with the virus.

The group of people attending the training session were "Quite diverse," she says, from many different social and economic backgrounds, both gay and straight. She says, "I hadn't really known any homosexuals before. I got to know a few of the people involved in the program and they became central to my life."

Support groups called "pods" are an integral part of the program for Buddies after the initial training. Ellen says, "My pod has been a really incredible emotional support for me. Even before I was matched with Thom, they helped me to get beyond my self-pity and to begin to believe in myself again. I was sure they thought, 'What is this eccentric older lady doing her?" For about three months, Ellen attended the pod meetings regularly every two weeks waiting to be paired with somebody. Ellen says, "I was a bit disillusioned that it took so long. Everyone else got paired up and I was feeling that maybe they didn't want me."

Finally, she was paired with Thom. She says, "He was somewhat stand-offish at first, but polite." There were several subtle put-offs in the beginning. "Thom would be sleeping when I called, or it wasn't a good time to talk. I felt that he was friendly, but that we weren't really going anywhere in our relationship - we were treading water."

"It wasn't easy for me," she goes on, "to start a new relationship with anyone at that time in my life. I was vulnerable and apprehensive about reaching out beyond what I had known in my own life."

"Thom set the ground rules for our relationship during the first few months. Gradually, he opened some doors and allowed me into his life. I think that the important keys to unlocking those doors were mutual trust, respect, and acceptance of each other as individuals. In retrospect, it is incredible how much we have grown as two people and in our relationship over the past two and a half years."

"Oh, we have our altercations at times, but it comes from truly caring and feeling for each other. I am not religious in a conventional sense, but I am deeply and spiritually moved by the depth of our caring and commitment to each other."

When she began in the program, Ellen had lots of free time. Now she has many demands, including her teaching at a technical college, her newly established Women's Center (WON), and other volunteer efforts - a boys' emergency shelter and a program for young girls at the MYC. "But," she says, "with all these activities, my relationship with Thom and my pod group remains central to me. This has been the real turning point in my life...and continues to be an incredibly positive experience."

As Ellen began her teaching job, Thom brought her into the age of computers. "Thom's expertise and teaching has been immeasurable. He's a real taskmaster! He made me learn about computers and programs to the point where I can now do some stuff I wouldn't have even dreamed possible a few years ago. Without his expertise, I'd definitely be somewhere else. He has given so much to me."

"I must admit that at the beginning, I was a bit frightened about dealing with a man dying, but now I am not afraid. Thom is a integral part of my life. When my children came back to me there were adjustments and changes. The kids love Thom and think he's great. He spent Thanksgiving and Christmas with us and is truly part of the family. The kids admire the reaching out that I've been doing. The experience has broadened me and affected my children in a positive way. I never would have thought to discuss with them how they felt about HIV or homosexuality. It is a wonderful thing for me to see how they love Thom."

Ellen goes on, "Thom was a different person when I first met him; so was I. We have both grown a lot. We respect where each other is. The only thing that I have truly given him is myself. And we have some really fun times together! By reaching out beyond myself, I not only found myself, but I also met my dearest friend."

"Brian Allen's mix of compassion and flexibility helps to make the Buddy Program work. I wish more people living with HIV/AIDS would give the program a chance. I wish more people not in the 'HIV community' would learn about the program and get involved and volunteer."

Director Brian Allan of Merrymeeting AIDS Support Services conducts the training sessions for the volunteer Buddies and oversees the pairing of the Buddy to the person living with HIV/AIDS. There are approximately 100 pairs currently in existence throughout the state of Maine. Recently 16 volunteers completed the training. They hailed from Bangor to Lewiston, from Boothbay to Yarmouth. If you would like to know more about the program, contact your case manager or contact Brian Allen directly at MASS, P.O. Box 57, Brunswick, ME 04011-0057 or call (207) 725-4955.

IN THE AFFIRMATIVE 5
LEGAL ISSUES
by Deborah Shields

Welcome to the LEGAL ISSUES column again - the place where you can contemplate all kinds of fun facts (who really deserves your Nancy Reagan dolls after you're gone?) and get started on a good night's sleep while your eyes pretend to move across the page and absorb information. In this issue, we explore the document known as the Durable Power of Attorney for Health Care. As with other Estate Planning documents, the Power of Attorney allows you to decide who will make decisions for you when you are no longer able to make them for yourself and allows you to choose someone besides your 'next of kin' for this role in your care. After all, why should dear old Aunt Erma from Dubuque have this power just because she's your only living 'kin' when you haven't seen her since your high school graduation 19 years ago?!

To start, let's clear up some possible areas of confusion. There are two kinds of Powers of Attorney (known also as P. of A.) - one is for financial matters and one is for health care. In some states, or within some law firms, these two documents may be combined into one; meaning that the person who you designate as your Power of Attorney has control over both your finances and your health care decisions when you become incapacitated. I would suggest writing two separate documents so that, for instance, your best friend Mary - the banker who faints at the sight of blood - uses her expertise as your financial Power of Attorney and pays your bills, signs checks, makes deposits, etc. when you are incapacitated. Then you can name your dearest friend George, - the nurse who can't balance a checkbook - as your Power of Attorney for Health Care. This article focuses on Health Care Powers of Attorney only.

When does someone have the authority to act as your Power of Attorney? Once you have drawn up this document, you must either be incapacitated or incompetent before someone else can act as your Power of Attorney. In other words, the power doesn't take effect immediately upon signing, rather, it takes effect when you are too sick to make decisions for yourself (this is known as a 'springing power' because it takes effect in the future). You may state explicitly in the document that your doctor must first declare that you are 'incompetent due to mental or physical incapacity' in writing before your Power of Attorney can act for you. You can also choose to draft a 'non-springing' Power of Attorney which takes effect immediately upon signing or when you turn the signed document over to the person named as your P. of A. This method can get a little messy and may result in the person named as your P. of A. having the powers to make decisions for you even if you might be capable of making them for yourself - unlikely but possible and why take the risk? In other words, explicitly state in the document when you want it to take effect, and, if you want it to begin when you are 'incompetent', then define that term in detail or request a signed note of incapacity from a doctor before your Power of Attorney can act for you. But also remember that, in case of emergency, you want this person to be able to act as your Power of Attorney as quickly as possible.

Because your P. of A. for Health Care essentially stands in your shoes and makes your health care decisions for you, it can be useful to decide medical treatment issues in advance and write these into the document. These medical treatment decisions may also be written into a separate document usually known as a 'Living Will'. To ensure that someone is named to enforce your medical treatment wishes, it is preferable to integrate 'Living Will' type decisions about medical treatment - or lack thereof - into a single document such as a Health Care Power of Attorney. In Maine, both Living Wills and Health Care Powers of Attorney are valid documents so if you choose to draw up separate documents make sure that your Health Care Power of Attorney is ready to follow the wishes stated in your Living Will.

You can choose to write a very simple Health Care Power of Attorney document which states that the person you name has the power to make all decisions regarding your medical care when you are unable to and which includes a backup person in case the first person named is out of town or unreachable. Or you can even name a group of people who have the power of decisionmaking by a majority of votes with one person named as the emergency decisionmaker. In other words, there is room for you to write these documents to suit your needs - this article aims to show you some of your options, but please discuss the details with your attorney.

You also have the option, in either your Living Will or your Health Care Power of Attorney, to offer as much guidance as possible concerning your future medical treatment. You may want to consider the following issues and incorporate them into your documents:

- who will be allowed to visit you in a hospital intensive care unit? (some hospitals only allow immediate family members to visit)
- do you want your Power of Attorney to decide who sees your medical records?
- do you want your Power of Attorney to choose any and all necessary health care practitioners for you if you have not already done so?
- do you want them to have the power to consent to or refuse any and all medical procedures, i.e. do you want life sustaining treatment, such as pacemakers, renal dialysis, respirators, etc.? under what conditions? do you want to undergo invasive surgery if it may prolong your life only several months?
- do you wish to spend your final days at home if possible?
- do you want intensive pain relieving measures used even if they could result in addiction or physical damage?
- do you want a 'Do Not Resuscitate' order in your charts? under what conditions?

The list could go on but you get the picture. You have the power to decide the amount of detail that you want in these documents. After you have completed them, please be sure that copies are placed in your medical records, given to all your medical care providers and to friends, family and caregivers so that they are all informed of your wishes. While it can be emotionally challenging to face these issues, it can also be empowering and may help give you a sense of control over your future medical treatment.

Deborah Shields, Esq. is a lawyer and the Executive Director of The AIDS Project. She can be reached by calling 774-6877.
PAWS (Cont. from page 3) kitten's parents', Poison and Mary Beth.

Since last August when Heaney started his regular visits, he's become well-acquainted with Enos and his furry friends. Heaney knows that Mary Beth likes to hide behind the television set and that Poison loves to have his head rubbed and that Dusty's right ear is sensitive.

"Part of the reason I want to help is because I love animals," says Heaney, owner of two cats, Spike and Isabel. "And because when the doctor first told me that I had AIDS, I was also told to get rid of the cats because of my health. But there was no way I could do that. That would have been terrible and stressful for me. My pets are important to me. They are my life."

The Los Angeles chapter of PAWS assists more than 500 people with AIDS. The volunteers help care for 760 pets, including dogs, cats, hamsters, snakes and one pig.

Besides dog walking and home visits, PAWS volunteers take pets to the vet. Currently PAWS/MAINE is seeking veterinarians to provide free or reduced fee services for checkups and regular office visits.

PAWS/MAINE has received great emotional support from the local community, including practical support from The AIDS Project, as well as our first donation of cat litter from Hastings D. F. Distributors out of Augusta.

Thank you all and please continue the much needed support.

For information on how you can become a part of PAWS/MAINE and to make donations of food, supplies and services or to volunteer, contact
PAWS/MAINE
(207) 871-9109
and talk with Charlie Wynott or Jon Piefer.

PEABODY HOUSE
by Chris Behan

Peabody House, Maine's first residence for people in the advanced stages of HIV disease, has begun renovation of the house it purchased last fall at 14 Orchard Street in the Western Promenade Historic District. Named for Frannie Peabody, 90 year old AIDS activist and humanitarian, the residence is being created to respond to the urgent need for housing and care for people with HIV disease. The 1900 Colonial Revival house has 18 rooms and will house six residents in private bedrooms and have an on-site manager, Mary Menair.

Mary Menair comes to Peabody House after years of work as the Executive Director of Hospice of Maine. Most recently she was running a full-service hospice organization in Maryland before she returned to Maine to oversee Peabody House.

Peabody House has as part of its mission "to provide a supportive, holistic, home-like environment...to maximize human dignity, individual autonomy and the right to self-determination." In that spirit, Peabody House organizers are paying special attention to the aesthetics of the home. Local decorators are donating furnishings and accoutrements. A generous local donor has made a huge contribution to create a healing garden and is working with a committee of avid gardeners to create a "sacred place" with fountains, flowers and birds for residents to enjoy.

The adaptive reuse of the house also requires that an elevator be installed, so residents can freely move about the building even if they are in a wheelchair or feeling fatigued. An addition is being made to the building to keep with its historic character. Total renovation, acquisition and interim costs for the project are over $750,000. To date $450,000 has been raised. Peabody House trustees and friends are actively fundraising. So far there have been over $180,000 in contributions from individuals, many in memory of people who have died from complications due to AIDS. The City of Portland has promised $100,000. It is anticipated that the house will open in the fall of 1994, probably in October.

In addition to the assisted living residence, Peabody House Incorporated, a non-profit organization, is starting a full-service home health care agency, called Peabody House Services, to serve those with HIV disease in the community and at Peabody House. Peabody House Services allows people to get care where they want it, in their home and to avoid unnecessary or prolonged hospitalization. Clients who need additional services or extra special attention will be able to move into Peabody House, the residence.

The AIDS Project is a separate organization from Peabody House, but has been encouraging its establishment and nuturing its growth because it will allow more support and housing in the care of its clients.

For more information call Mary Menair at 774-6281
The Maine Community AIDS Partnership Survey

Information from 140 surveys returned to the Maine Community AIDS Partnership and from several focus groups conducted by MCAP has been analysed and collated. A report on the results of all this information is still being finalized at this time and will be made available to HIV/AIDS organizations and interested persons later this year.

Kate Perkins, project coordinator for MCAP, says that the information and opinions gathered from persons with HIV/AIDS in this survey will serve as a tool for developing future proposals and projects. She believes the survey will be a persuasive research document to be used in writing grants and obtaining new funding. It is hoped that community based organizations will use this survey to obtain funds for continuing services as well as expanded programs. Ms. Perkins states that it will highlight the needs of people living with HIV/AIDS in Maine and the opportunities for organizations to provide the supportive services necessary throughout the state.

Opinions on such topics as to the needs of persons with HIV/AIDS were gathered and broken down into categories that included such things as sexual orientation, gender, and health status, among others. Areas of need noted from the response to the survey include, but are not limited to, such things as the issues concerning discrimination, educational concerns, basic living needs, medical and dental services and emotional support.

Ms. Perkins thanks all those who participated in this project and says that a press release will probably announce the findings of this project to the general public.

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EVERYONE IS WELCOME
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Write to us and tell us what you think of IN THE AFFIRMATIVE.
Tell us you love us, Tell us you hate us, Tell us you were moved, Tell us you were irritated.
We can take it all. Tell us what you'd like to read about in these pages.
Share your stories with us, your trials and triumphs, how your lives have changed because of HIV/AIDS.
If you'd prefer, we will keep your letters and stories confidential, just include your name and phone number so that we can verify your story and discuss with you how we can present your story to our other readers.

AIDS Update
AIDS - FROM THE BEGINNING: 339,250 CASES IN U.S., 205,390 DEATHS
IN MAINE - 480 CASES OF AIDS (SO. ME 251, CT ME 161, NO ME 68), 221 DEATHS
NATIONAL STATISTICS AS OF 9/30/93 - MAINE STATISTICS AS OF 12/31/93

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