
Mick Martin
The AIDS Project

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Daniel Schnorbus Introduces Himself As TAP’s New Client Services Coordinator

I would like to introduce myself. My name is Daniel Schnorbus and I am the new Client Services Coordinator of The AIDS Project. I have replaced Rodney Mondor. We all wish him the best of luck in his work at the University of Southern Maine.

I have recently relocated to Portland from Indiana where I graduated from Franklin College with an undergraduate degree in psychology. I have had the privilege of working with a variety of non-profits including Habitat for Humanity and The Sisters of St. Francis at Michaela Farm. It is my great hope that I can contribute to the sense of community and camaraderie at The AIDS Project by utilizing the skills I learned at those organizations. I look forward to acting as your Client Service Coordinator.

From the buzz around the office I have learned that we have a dedicated pool of reliable volunteers. On behalf of The AIDS Project and those we assist, I want to thank them for their diligent work. Their efforts are greatly appreciated and needed. With the assistance of volunteers we are able to do our jobs much more efficiently. We cannot thank them enough for their contributions.

In this position it is a personal goal to make the volunteer experience at The AIDS Project as rewarding and simple as possible. Volunteer work is a mutual give and take when the process enriches both the helper and the one that is helped. It can be inspiring, emotional, and sometimes even humorous for all parties involved. In my adventures with helping out I have learned that I always get much more from the experience then I give.

If you would like to join our existing group of volunteers to offer some of your time, please contact us. We would appreciate what you have to offer and I am confident that it would be a rewarding experience for you. We have a variety of tasks that need to be accomplished. One is certain to be tailored to your personal strengths, preferences, and schedule.

Thanks again for all of the work that volunteers have done and, of course, we welcome new volunteers. We look forward to hearing from you.

Editor’s note: A big welcome to you, Daniel, and all the best in your new job! To contact Daniel at TAP, call 774-6877.
What is it about this time of year that seems so peaceful on the one hand and so stressful on the other hand? Perhaps the stressful part is due to our desire to have a perfect holiday season. A few years back, it dawned on me that I wasn’t really enjoying the holidays. The expectations that my family and I had were a little out of line when it came to the reality of the season. We were working so hard to make Christmas such a perfect time that we couldn’t possibly have had a happy day. We would fret and worry so over all the little details that we were beginning to miss the big picture. Which is that the holidays are about getting together and enjoying each other’s company. So if the house isn’t spotless and the food isn’t to everyone’s exact specifications, it doesn’t matter as long as we remember it’s all about being together, sharing memories and sharing some laughs. I am happy to report, we’ve gotten much better at enjoying the holidays. I truly hope you, too, enjoy the holiday season.

With the new year just around the corner, I’d like to stop for a second and just say thanks to all who have made this past year interesting, to say the least. Thanks to my family and friends for your aide and comfort. I am also particularly thankful to all the folks at The AIDS Project. You are a dedicated group of individuals who do great work together. The work never ceases, and you rise to the challenge every day.

There is one person in my life that I would be remiss if I didn’t single her out. That’s my Mom. Suffice it to say, Mom has made my life very comfortable. She still can make me laugh at the silliest little things. And my three brothers and I know that she loves us very much. And we love her back.

The year has not always run smoothly. News of better treatments and more treatment options for people with HIV and AIDS is good, but that is leavened with the knowledge that not all have benefitted from the good news. Some people who are living longer are not necessarily living better. People are still getting sick and dying from AIDS. And, horrifically, the number of new HIV infections is not dropping at all. There is no end in sight.

Recently a person I first met at an HIV support group ten and a half years ago (at The AIDS Project back when it had office space on Deering Street) died. The obituary made no mention that he had AIDS. Was it shame or merely privacy that made the family exclude this highly significant fact? I don’t know. It reminded me, however, that there are still many people with HIV and AIDS who are afraid to be open about their status. Some worry about being rejected by family and/or friends. Some worry about the reaction of their co-workers or supervisors. Some worry about their personal safety if they make their HIV status known publicly. We may have come a long way with treatment for this disease, but there is still a lot of fear out there. This fear can translate into depression, loss of self-esteem, not seeking medical treatment, and being isolated from the world. There is still a lot of work to be done in helping people come to terms with their lives. Lives significantly affected by HIV and AIDS.

One of the folks who has made AIDS better known in Maine, who helped to drag it out of the closet, is Frannie Peabody. Well into her 90’s, Frannie continues to get out in public and beat the bushes for The AIDS Project and Peabody House. She is a treasure. Thanks to Frannie for all her good work and personal attention to people with HIV and AIDS.

Last fall, I gave Frannie a ride to and from a board meeting for The AIDS Project. After I dropped her off at her home (politely walking her into her home and making sure she was all set, as I was brought up to do these things), I backed out of her driveway and drove past her front door. Standing inside the door and looking through the window, Frannie waved goodbye as I headed home. It reminded me very much of the many times I visited my grandmother and upon driving away, she would wave to me from her window. My grandmother, Rose, died nearly six years ago. It was always so sweet when my grandmother waved goodbye, and so comforting. Frannie is a comfort to so many people and in ways even she might not know.

H. L. Mencken once wrote that his job as a journalist was to “comfort the afflicted and afflict the comfortable.” HIV and AIDS is often uncomfortable, for those infected and for those who live in fear of it. For those who are beginning to get a little too comfortable, and a little too unconcerned, about HIV, I say don’t rest easy. The epidemic is far from over. For those who know full well what it is like to be HIV-positive or to be diagnosed with AIDS, I hope that some comfort comes to you and the ones you love at this special time of year.
Editor's Note: As 1998 draws to a close, it is a good time to reflect on the fact that it takes a lot of dedicated people to keep The AIDS Project working to fulfill its mission of providing support services to people infected and affected with HIV and AIDS and to provide prevention education to as many people as possible in the four counties we currently serve in southern Maine. Also, we give thanks to the many volunteers who over the years have helped make the lives of people with HIV and AIDS more bearable and who have made the work of The AIDS Project run more smoothly.
Susan Parr, one of TAP’s case managers, will be starting an Expressive Therapy group for people living with HIV and AIDS. In this group, creativity will be explored through art, movement, music, storytelling, play, and writing. Absolutely no experience is needed! The group will provide time for self-discovery, reflection, and relaxation. Please call Susan if you are interested in the group or would like more information. Call Susan at TAP at 774-6877.

Expressive Therapy Group for people with HIV/AIDS

For those persons with HIV who attended this past summer’s Reconstruction Forum, Randy Norcross of the Maine AIDS Alliance has passed along some of the comments from the last session where the participants expressed further needs around rebuilding their lives. The Forum explored the particular needs of those folks with HIV who are exploring a longer future than they had previously thought possible.

Some of the comments and conclusions were:

1) We need a group in order to explore dating issues. We don’t know how to go about dating again. This group needs to include both HIV-positive and HIV-negative persons. We don’t know what those who are HIV-negative expect or fear. This group will need a professional facilitator.

2) Each area in Maine needs a case manager who is specifically trained in rehabilitation issues. We mean the kinds of issues explored this summer in the Reconstruction sessions. This service would have to be designed for people who are living longer and take into consideration all of our unmet needs.

3) We need a support group to look at “reasonable expectations” for us. We can’t live up to the expectations of the media.

4) We need a workshop in career counseling. This should be done in two sessions. The first group should include HIV-positive persons who make their career/work needs known. These must become concrete and put onto paper. The second group should include an agency, like the Training Resource Center in Portland, to consult with us.

5) We would like each AIDS Service Organization that publishes a newsletter to have a “Reconstruction Corner” to discuss the issues described in these unmet needs.

6) We need a group or workshop to discuss the spiritualism that allows each of us to continue. We are not talking religion here, but there is a spiritual layer that each of us relies on. We need to be able to articulate that for ourselves and others.

7) How do we reach the “silent”? How do we reach those HIV-positive persons who are not connected to the system by choice? How do we keep them appraised of what is available?

8) We need an information packet with info provided on each of the topics covered by the Reconstruction’s eight sessions. Every AIDS Service Organization needs to have such a packet, to be made available through their case management departments.

Having talked to Randy Norcross about these results, he told me that the first area he felt needed to be addressed was the training of case managers throughout the state of Maine around the needs of people with HIV who are trying to plan for the future, whether that means going back into the workforce or some other future endeavors. Randy is spearheading the follow-up to Reconstruction and he will keep us informed.
Indinavir (Crixivan®)
Twice Daily Dosing Warning!

Project Inform (11/98)

New information from a study of indinavir (Crixivan®) has shown that a twice daily dosing regimen (1,200 mg taken every 12 hours for a total daily dose of 2,400 mg) is not as effective as the standard three times daily schedule after 24 weeks. As a result, Merck, the manufacturer, stopped the part of the study that uses twice daily dosing and has notified the public of the new findings. These results are contrary to a previous, smaller 24-week study which suggested that twice daily dosing was at least equivalent to the standard dosing regimen (800 mg taken every 8 hours for a total daily dose of 2,400 mg). Based on these findings, the company is encouraging everyone using twice daily dosing to switch back to three times daily dosing.

This Merck 069 study included people who had never previously taken a protease inhibitor and had never previously taken 3TC. The regimen included AZT, 3TC and indinavir, either given twice or three times daily. All participants received twice daily dosing of 3TC.

After 24 weeks of study, 91% of those receiving three times daily dosing had HIV levels below the limit of detection (<400 copies HIV RNA), computed to 64% on twice daily dosing. One important lesson from this study is that after 16 weeks of observation, the twice daily dosing schedule appeared equivalent to the three times day regimen. By 6 months, however, the superiority of three times daily dosing became very apparent.

Since this is a very preliminary look at the results, there are still unresolved questions. For instance, did people receiving the twice-daily indinavir regimen, who also received AZT twice daily (300 mg twice a day for a total daily dose of 600 mg), have more side effects because of the high peak drug levels of both drugs (the risk of side effects increases when drug levels are increased)? Other questions are raised as well. Would these results be different if people started out on d4T instead of AZT as it is generally better tolerated? Would someone who started on three times daily indinavir and went below the limit of detection do as well if they switched to twice daily indinavir compared to if they stayed on a three times a day regimen? Are people who simply cannot adhere to a three times daily dosing regimen better off continuing to struggle with that regimen (and possibly failing to adhere) or committing to a potentially less potent twice daily dosing with better adherence? In any case, it’s important health care providers and people living with HIV are aware of the superiority of the three times daily dosing of indinavir, as many doctors and patients have already made the switch to twice daily dosing.

Indinavir, in combination with another protease inhibitor, is still being studied for twice daily dosing in other studies. One combines indinavir with ritonavir. Ritonavir is able to substantially increase indinavir levels in blood as well as slow the rate at which indinavir is passed out of the body. Preliminary, short-term studies appear to show that this regimen allows indinavir to work well with twice daily dosing, while the combination also seems to eliminate the need to avoid taking food with indinavir.

However, it’s important to recognize this is based on very early data. Studies are ongoing to determine the optimal doses of indinavir and ritonavir when used together. Another study combines indinavir with nelfinavir with both drugs being taken twice a day. Longer-term data will help confirm whether the drug is useful when used in these combinations in twice daily dosing regimens.

Caution About Regimen Changes

The lesson learned here is something that Project Inform has been cautioning about for some time with regard to simpler and easier regimens using current available therapies. When these drugs were approved, the reason they were dosed according to schedules in their label instructions (e.g. three times daily) is because studies demonstrated these schedules were necessary to maintain optimal blood levels of drugs. While people want, need and deserve simpler regimens, simply changing a regimen from three times to twice daily dosing is not the solution. The lesson here is that it takes larger, long-term studies to accurately determine how well a drug works in different dosing regimens. It can be potentially dangerous to make treatment decisions based on small exploratory studies.
In The Affirmative

Treatment Flushes HIV From Blood
USA Today (11/16/98)

Three HIV-infected patients appear to have had virtually all of the virus cleared from their system following treatment with standard anti-HIV drugs and interleukin-2. The treatment was designed to flush HIV from latently infected cells in order expose it to the anti-HIV medications. Fourteen patients were treated in this manner; investigators, led by Tae-Wook Chun, could not grow live HIV from 330 million immune cells taken from three of the patients.

However, Robert Siliciano of Johns Hopkins University cautioned that even with the large number of cells taken, the three patients could still harbor the virus. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, also warned that it is still too early to speak of the treatment as a cure. He said that the patients will soon be taken off their drug regimen to determine if there are hidden areas of infection. "It's conceivable that we'll take these people off their drugs and the virus will come roaring back from a reservoir we didn't find," noted Fauci.

The Trouble With Ritonavir
POZ (11/98)

Abbott Laboratories indefinitely halted in July production of the protease inhibitor ritonavir over concerns about crystals in the drug's capsules. The crystals are not contaminated, but Abbott does not yet know what caused them or how they can be removed.

Although, the defective drugs were caught before distribution, pharmacies may soon run out of existing stocks. Until the problem is solved, ritonavir capsule users can switch to the liquid version, which is identical in composition and price to the capsules. Differences between the two forms include the fact that the liquid should not be refrigerated -- while the capsules should -- and that the liquid ritonavir has a high alcohol content, possibly raising concerns for recovering alcoholics or people with liver disease or hepatitis.

Many people have also said that the liquid tastes unpleasant, a factor that could raise adherence issues for those who cannot stand to take it.

Coping with Ritonavir (Liquid)
Project Inform (11/98)

Unlike the liquid ritonavir formulation used in experimental studies, the current liquid formulation should NOT be refrigerated, but rather stored at room temperature (between 68-77 degrees F or 20-25 degrees C). Additionally, before each use the bottle needs to be shaken well and used within 30 days of receiving it from the pharmacy. If it is stored in the refrigerator there is greater risk the crystalline structure will appear, and if stored in too warm an environment it might lose anti-HIV activity. Should the crystalline structure appear it can be clearly seen through the bottle when held up to light. Vigorously shaking the bottle can dissolve the crystals and the drug will work normally. However, if the crystals do not dissolve, a new prescription needs to be obtained.

Unpleasant Taste

The liquid formulation has a very unpleasant taste. The drug can be combined with chocolate milk or nutritional supplements such as Advera or Ensure before each dose to mask the taste (but don't combine them more than an hour before taking the dose). Fatty and/or salty foods can also mask the taste. Taste tests show that the following can help with the taste: Nutella hazelnut spread on graham crackers; Riesen chocolate chew; oats and honey granola bar; and toast crackers with peanut butter. Other suggestions include:

- drinking the liquid solution with a straw placed at the back of the throat, thereby bypassing the taste buds,
- sucking on a frozen Popsicle before and after taking the drug to numb the taste buds,
- using a syringe to fill empty capsules with the liquid, and swallowing the capsules,
- eating something very sweet before and after to overwhelm the taste buds.

People having problems with side effects should notify a physician. A different treatment regimen may be needed. Switching from ritonavir to another protease inhibitor or non-nucleoside reverse transcriptase inhibitor may require dose adjustments of drugs in the new regimen, as ritonavir blocks an enzyme that these drugs require to be processed in the body. If a person chooses to stop taking the drug without replacing it, it is important to stop all HIV antiviral medications together.

This avoids creating a period of weakened therapy that would encourage development of resistance. Preventive medications for opportunistic infections, like Dapsone or Septra/Bactrim to prevent PCP should be continued, however.

The liquid formulation of ritonavir contains 45% alcohol so people in alcohol recovery programs need to consider this before starting to use the liquid. Furthermore, ritonavir is not recommended for people with hepatitis B or hepatitis C virus.

Switching vs. Sticking with Ritonavir

This question is now being faced by almost every one who has used ritonavir. Though there isn't one right answer for everyone, a few guidelines are possible. Ritonavir, when used properly, is among the most potent protease inhibitors. It should not be discarded casually. An alternative regimen might or might not offer the same level of potency.

* If treatment with ritonavir is marginal or beginning to fail, this is the time to switch. When switching, it might be wise to consider getting a resistance test done, if possible, to guide the next choice of therapy.

* If you really like the results you're getting with ritonavir, just stick with it and try to cope with the taste issue.

* If treatment is working and you can adhere well, try the liquid for a week to see if you can live with it. Many people can. Use of the liquid will only be temporary. If you find it unacceptable, almost any other protease inhibitor is a reasonable substitute.

If you decide to switch to something else, please consider the following:

* Review available materials (Project Inform and others) about the relative potency, durability and side effects of the available drugs.

* Unless you have developed resistance to ritonavir, you should be able to switch back to it whenever desired.

* The value of switching to a so-called "protease sparing" regimen is unclear for people with prior use of protease inhibitors.

* If you have used all the drugs in your combination for a year or longer, consider changing all of them at once.
Poll Shows Cavalier AIDS Attitude
UPI (11/30/98)

A Harris poll by the American Foundation for AIDS Research (AmFAR) indicates that most Americans are not particularly concerned with their risk of contracting HIV. According to Mathilde Krim, chairperson of AmFAR, "Most Americans think they are more likely to be shot by a total stranger or go completely deaf rather than be infected with HIV, the virus that causes AIDS.” Fear of AIDS ranked last on a list of 11 different accidents and illnesses in the poll. Despite the fact that deaths due to AIDS have decreased in the United States, AIDS is still a major global problem. In the United States, half of all new HIV infections occur in people under the age of 24 years; however, respondents aged 18 to 24 also ranked HIV/AIDS last in the survey.

Urine Test Finds HIV
When Blood Test Can’t
Salt Lake Tribune Online (12/03/98)

A large-scale study of HIV screening found that in some cases urine tests showed antibodies against HIV-1 in some low-risk individuals, while blood tests from the same individuals did not.

According to the Clinical Reference Laboratory in Kansas, one of the largest testing labs in the country, approximately one of every 1,000 low-risk individuals tested positive for HIV-1 antibodies in their urine but not in their blood. Of 25,000 subjects, 24 were found to have the antibodies in their urine, but not in their blood samples. The lab suggests that people who receive HIV tests receive both blood and urine assays. Some researchers note that the findings support the idea that the virus can “compartmentalize”, reproducing and isolating in tissues away from the blood.

"With HIV, you have to kill all of the virus no matter where it lurks in blood and tissue. Even a few surviving viruses can sow the seeds of life-threatening infection throughout the immune system all over again”
- Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Disease, commenting in USA Today that there is no cure for AIDS.

FDA Approves Nevirapine
for Pediatric HIV Infection
Reuters (11/24/98)

The Food and Drug Administration approved nevirapine, a non-nucleoside reverse transcriptase inhibitor (NNRTI), for use in HIV-infected children. Nevirapine is the first NNRTI to be approved for children. Clinical trials showed the drug to effectively suppress HIV-1 viral load in children and to be well-tolerated, although one study found that 16 percent of children on the drug developed a related rash.

Some States Refuse to Pay for HIV Drug
Unless Maker DuPont Agrees to Discounts
Wall Street Journal (11/19/98)

A number of large states, including New York and California, have decided not to pay for DuPont's HIV drug Sustiva unless the drug maker agrees to discuss significant discounts. Although the drug, which can be taken just once daily, has been widely accepted since its launch in September, states are balking at the steep annual wholesale price ($3,920) which is roughly double the price of two other drugs on the market.

With the publication of new guidelines, the Centers for Disease Control and Prevention will urge states to institute mandatory reporting of HIV in order to track the disease. While the CDC advocates name-based reporting, individual states will be able to decide what sort of reporting system they wish to use. To ensure confidentiality, HIV reporting will have to conform to certain requirements created by the CDC no matter what type of system is instituted. Many agree that HIV reporting is imperative to generate accurate statistics concerning the spread of the disease; however, some fear that the use of name-based HIV reporting will result in a breach of confidentiality and could deter people from getting tested.

Some states have opted to use “unique identifier codes”, which report HIV cases without reporting patient names. The use of unique identifiers, though, may not be advantageous for partner notification and could be less practical. In either case, the CDC still advocates the continued availability of anonymous testing sites. The new guidelines will be published in the Federal Register.
**MEDICAL ASSISTANT FUNDS**

An important reminder to clients:
There are funds available to TAP clients with financial need for the following items: Routine Dental Care, Routine Eye Care and Eyeglasses, Vitamin Supplements, Non-Prescription Skin Care Products, and Non-Medicaid Medication Co-pays.

There is a dollar limit to how much a client can receive in any fiscal year. Contact your case manager for assistance.

**FREE LUNCH**

Enjoy a free lunch at The AIDS Project every Thursday at noon. Join other clients and TAP staff for a great meal, good conversation, and very good company. Drop on by Thursdays at noon!

**IMMEDIATE SEATING**

For free tickets to area events as they become available, sign up for "Immediate Seating." Call TAP at 774-6877 for more information.

**I.V. LEAGUE**

Meetings of the I.V. League support group are held on Wednesdays at 11:00 a.m. at the Parkside Community Center, 94 Mellen Street, in Portland.

For more information, call 874-8775.

**THE MEETING PLACE**

This room is used by TAP in Portland for support groups, counseling and testing, and some client/case manager meetings. Located in Suite 632, it provides more privacy for people served by TAP.

Enter from the High Street side of the building.

**FOR YOUR INFORMATION**

**TAP ON-LINE**

Visit our new website at: "www.aidsproject.org"

To e-mail The AIDS Project, send your message along to "tap@aidsproject.org"

**HIV WEBSITES**

Check out these websites:

www.hivpositive.com
www.thebody.com
www.projinf.org

for info on HIV and AIDS.

**AIDS HOTLINES**

Questions about HIV/AIDS?

Call toll-free

National AIDS Hotline:
1-800-342-2437

Maine AIDSline:
1-800-851-2437

Maine Teen Hotline:
1-800-851-2437

(on Wednesdays from 6-9pm)

**FOR PEOPLE INFECTED AND AFFECTED BY HIV/AIDS**

**TUESDAYS**

Time: 10:30 a.m. to noon

**Group: HIV Infected/Affected Drop-In Support Group**

A meeting for people living with and affected by the virus.

Location: Portland, TAP, The Meeting Place, Suite 632.

Contact Randy May at TAP at 774-6877 for more information.

Time: 1:30 p.m. to 3:00 p.m.

**Dates: Started September 22nd, Meets every other Tuesday**

**Group: Women with HIV**

A bi-weekly meeting of women living with HIV.

Sponsored by The AIDS Project (TAP) and The AIDS Consultation Service (ACS) at Maine Medical Center.

Location: Portland, ACS, 52 Gilman Street.

Contact Janine Collins at TAP at 774-6877 or Cindy Luce at ACS at 871-2391 for more information.

Time: 1:30 p.m. to 3:00 p.m.

**Group: People Living with HIV**

An ongoing drop-in support group for people living with HIV.

Location: Auburn, TAP, One Auburn Center.

Contact Diana Carrigan at TAP at 783-4301 for more info.

**THURSDAYS**

Time: 10:00 a.m. to 11:30 a.m.

**Group: HIV Infected/Affected Drop-in Group**

A TAP-sponsored meeting for people living with and affected by HIV/AIDS in southern Maine.

Location: Sanford, Unitarian Church, located at the corner of Main St. (Rte. 109) and Lebanon St. (Rte. 202).

Contact Getty Payson at TAP at 985-8199 for more info.

Time: 12 noon

**Group: Open Lunch for TAP Clients/Staff**

An informal luncheon gathering of TAP staff and clients.

Location: Portland, TAP, Conference Room.

Contact Randy May at TAP at 774-6877 for more information.

Time: 5:30 p.m. to 7:00 p.m.

**Group: People Living with HIV/AIDS**

A drop-in support group for anyone with HIV/AIDS.

Location: Portland, TAP, The Meeting Place, Suite 632.

Contact Randy May at TAP at 774-6877 for more information.