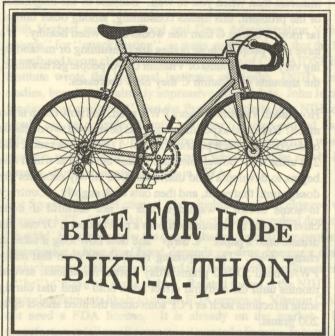


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PUBLISHED BY THE PEOPLE WITH AIDS COALITION OF MAINE

APRIL 1991

VOLUME 3 NUMBER 4



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BIKE-A-THON

The PWA Coalition of Maine has announced their first ever Bike For Hope Bike-A-Thon, slated for April 27, 1991 at 10:00 AM. The Bike-A-Thon Committee has been meeting for weeks now putting the final touches on, what promises to be, a fun time for all participants.

St. Peter's Episcopal Church will be the start and finish point for this 27 mile route that will take riders from downtown Portland to the mid-way point at Cousins Island. Central Maine Power Company has been very forthcoming in providing a special area for Bike-A-Thon riders to rest and refresh before continuing on the last leg of the ride.

Bike shops throughout the Greater Portland area have been contacted to provide special technical assistance to riders. Repair supplies and people to repair bikes will be provided, as will registration forms and pledge sheets at each owners location.

Kim Burch of Graffiti's in Portland has donated his services to design and print sweatshirts, T-shirts, and buttons for the run. Wait till you see the great colors we've chosen.

In addition to the stops for refreshments along the Bike-A-Thon route, and the mid-point stop at Cousins Island, a lunch has been planned at the conclusion of the ride. The lunch will be served at St. Peter's Episcopal Church. St Peter's has been very gracious to open their facilities for the event.

This event will be open to people of all ages, so if you have business associates, friends, children, or other family members who would like to join in the fun, get in touch with us at The PWA Coalition, 377 Cumberland Avenue, Portland, Me. 04401, or phone: 207-773-8500.

All the information you will need to prepare for the Bike-A-Thon is provided on page 6 and 7 of this month's newsletter. Get your sponsors signed up now, and see you on April 27!!

VITAMIN C THERAPHY FINALLY GETS SOME SCIENTIFIC VERIFICATION

by Bob Lederer

A recent test-tube study of Vitamin C (ascorbate) against HIV has brought this widely used AIDS treatment into a new and much deserved spotlight. The research results, published in September by the Linus Pauling Institute of Science and Medicine in Palo Alto, Ca., found that Vitamin C strongly suppresses the activity and growth of HIV in T-cells, without causing toxicity. High dosages, equivalent to a minimum of 10 grams taken orally, appear to have the strongest effect. (This compares to the government's "Recommended Daily Allowance" for C of 60 milligrams 0.6% of that level). These results, combined with the clinical data described below, reveal yet another case where drug-focused government AIDS researchers have neglected a vital avenue for clinical trials.

DRAMATIC RESULTS FOR YEARS IN PWAS

While the new study is welcome news, it is hardly surprising to PWAs and health practitioners who follow trends in alternative treatments. For over 7 years, a growing number of doctors and nutritionists have been supervising hundreds of PWAs on high doses of Vitamin C, often obtaining dramatic results. Several physicians with considerable AIDS research and clinical experience have observed such effects as:

Prevention of Pneumocystis carinii pneumonia (PCP) over an extended time period Major shortening of PCP episodes Amelioration of allergic reactions to antibiotics for PCP and other opportunistic infections Lessening or disappearance of KS lesions After several months of therapy, dramatic reduction in HIV activity, as measured by p24 antigen and HIV antigen tests

How does ascorbate - which researcher Linus Pauling and others have found effective against such acute viral infections as the common cold, flu, hepatitis-B and herpes simplex - have such powerful effects? The mechanism of action is still not understood, but there are two theories. One says that the substance causes degradation of the virus's genetic material. The other posits that Vitamin C is a scavenger of free radicals - toxic compounds formed by the body which are increasingly being identified as a key factor in many diseases.

In addition, studies have shown vitamin C to increase production of antibodies, reproduction of T cells, and synthesis of interferon, an immune-boosting chemical. But why wouldn't a "standard dietary intake of Vitamin C be adequate for PWAs? First, many nutritionists have severely criticized the ultra-conservative government guidelines for vitamin and mineral needs, which are based on the general anti-nutritionaltherapy line dominating the medical establishment. More important to PWAs is the analysis of Russell Jaffe, a New Jersey M.D. and researcher who had developed a highly scientific holistic AIDS treatment protocol. "When you're sick, your body uses and burns up much larger quantities of vitamins and minerals than when you're well. Because of the magnitude of the problem, this means consuming, among other things, far more Vitamin C than one would need when healthy. We have seen people whose bodies are consuming or metabolizing very large amounts of Vitamin C. As people get healthier, the amounts of Vitamin C they need decreases."

How much Vitamin C does a PWA need, and how much is too much? Repeated experimentation has developed two methods of determining each person's needs: 1) bowel tolerance, and 2) a urine test. Bowel tolerance means the level at which one begins to develop a mild diarrhea. One slowly escalates the dosage until that point, and then cuts back slightly. (Contrary to some doctor's warnings, this is not harmful if done carefully and in consultation with a practitioner.) Or one can urinate onto a paper "C Strip" and note how long it takes to change color. The surprising results have been that many PWAs need 50-100 grams a day - often for at lease several months until the antiviral effect takes hold - and that during acute infections such as PCP sometimes the need shoots up to 200 grams.

There are several forms and methods of taking C-tablets, powders, intravenous solutions (either doctor or self-administered). Each person has different needs and responds better to one form/dosage than another. (For example, some are allergic to certain corn-based ascorbate formulas.) So I strongly recommend you investigate the resources listed here and only use megadose C under a knowledgeable practitioner's care.

SIDE EFFECTS?

What about side effects (aside from diarrhea)? In an article in the 9/21/90 issue of AIDS Treatment News, John James quotes a dietician who warns that megadose C may cause deficiencies of vitamin B12 and copper. The 1974 study underlying this claim was later criticized for using "inefficient, non-standardized methods" and was contradicted by subsequent studies. Undocumented claims of toxicity, such as acisosis

Continued to Page 3

and kidney stones, have also been found to lack foundation. The B-12 study's distortions, and its orchestrated wide publicity, are typical of the tactics used by the co-author, Victor Herbert, M.D., a leader of the medical industry's National Council Against Health Fraud. Herbert and the Council have dedicated themselves to single-minded attacks on the use of alternative treatments - and particularly vitamin therapy - for any health problem. At the Council's September conference in Kansas City, Herbert called the Pauling Institute's work "silly" and "Quackery", claiming "Vitamin C doesn't help AIDS patients - it kills them."

FEDS REFUSE CLINICAL TRIALS

With Herbert receiving Food and Drug Administration "distinguished service awards" for "quackbusting", is it any surprise, then, that the federal government has refused to run clinical trials on megadoses of C for AIDS? In 1985, the Pauling Institute wrote the National Institutes of Health, (NIH), proposing just such studies, based on the already impressive clinical data. John James' article says "no funding was available." But the Pauling Institute says NIH told them such trials would not be considered until laboratory studies proved ascorbate's anti-viral effects. Translation: Until test tube evidence shows why it works, no government research will be done on a treatment which - unlike newly-invented drugs has already shown dramatic benefits in PWAs.

For 5 years, the NIH clinical trial pipeline has been clogged with such anti-viral drugs as AZT, ddi and ddC. This reflects the entrenched domination of the federal "health" bureaucracy by the major pharmaceutical companies - from the primary investigator whose livelihood depends on drug company consulting fees to the senior bureaucrat looking forward to a fat job with a multinational if he (universally a "he") "plays his cards right." Related to this is the NIH's acknowledged bias towards treatments likely to obtain FDA approval. Vitamin C is not a drug and does not need a FDA license. It is already on the market. Even if one of its manufacturers (all small companies) wanted a license - to legalize claims of medical efficiency, gain physicians attention, and facilitate insurance coverage - surely none could afford the estimated \$200,000.00 in bureaucratic costs. So the system is rigged against non-drugs.

RESOURCES

Linus Pauling Institute of Science and Medicine 440 Page Mill Road Palo Alto, Ca. 94306 (415)-327-4064

> Dr. Robert F. Cathcart III 127 2nd Street Los Angeles, Ca. 94022 (213) 949-2822

Dr. Russell Jaffe Princeton Bio Center 862 Rt. 518 Skillman, NJ 08558 (609) 924-8607

THE PWA COALITION OF MAINE and LIVING ROOM NORTH

are located at

377 Cumberland Avenue Portland, Me. 04101 Phone: 207-773-8500

Hours Open Monday - Friday 10:00 AM - 4:00 PM

Lunch Served Mon/Tue/Wed/Fri 12:00 AM - 1:30 PM

Wednesday Night Dinner 6:00 PM

Some Extended Hours
Call Ahead for Extended Hours

Special Events Posted Please Check Calendar

MAILING LIST

To preserve the confidentiality of those on our mailing list, our list is **NEVER** given to other organizations. The newsletter is mailed with only The Living Room North and street address as the return address. We encourage those interested in the newsletter to add your name or organization name to our mailing list. We appreciate your need for privacy and will protect your right to privacy by not printing references to AIDS on the outside mailer.

EDITORIAL POLICY

The Scoop reports events in the State of Maine and elsewhere. We do not necessarily agree or endorse all events or points of view.

NAMES PROJECT/MAINE AIDS MEMORIAL QUILT TOUR

The Names Project/Maine AIDS Memorial Quilt is once again on display. This time around the quilt is being shown on a state-wide tour of Maine's universities.

The quilt has been seen by thousands of people throughout the state of Maine. Each panel in the quilt carries the story of a loved one who has died from AIDS. Spouses, mothers, fathers, brothers and sisters, and children, who want to keep the memory of their loved one from dying have linked their quilt panel with others to keep their memory alive.

If you have not experienced the powerful message of the AIDS Memorial Quilt, you should plan to spend some time at one of the following tour locations:

UNIVERSITY OF NEW ENGLAND BIDDEFORD

April 1, 1991 through April 5, 1991 10:00 AM to 7:00 PM Daily Contact: Brian Doyle - 283-0171 Ext. 595

UNIVERSITY OF MAINE RUMFORD/MEXICO

STUDENT CENTER
April 8, 1991 through April 10, 1991
8:00 AM to 10:00 PM Daily
Contact: David Ackley - 364-7882

UNIVERSITY OF MAINE - PRESQUE ISLE

April 23, 1991 10:00 AM - 3:00 PM Contact: Erlene Clayton - 764-0311

UNIVERSITY OF MAINE - MACHAIS

April 24, 1991 10:00 AM - 3:00 PM Contact: Suzanne Mace - 255-3313

BRIDGETON ACADEMY - BRIDGETON

April 28, 1991 2:00 PM Contact: M. Lou Terry - 647-8084

COLBY COLLEGE - WATERVILLE

May 2, 1991 10:00 AM - 3:00 PM Contat: Nicki Vaydeboncure - 877-7931

COLLEGE OF THE ATLANTIC BAR HARBOR

May 6, 1991 through May 9, 1991 For Times Contact: Martha Greenley - 288-5015

CATHEDRAL CHURCH OF ST. LUKE STATE STREET - PORTLAND

May 19, 1991
6:00 PM - 9:00 PM
8th Annual International
AIDS Candlelight Memorial
Contact: David Ketchum - 934-4997



FROM MY CORNER OF THE OFFICE...

Spring has finally come! I know for sure because the bulbs that Sean and I planted last fall are up and in bloom...and the ideas and plans from this past winter are also up and in bloom.

The Bike-A-Thon and May NAPWA Conference committees are finalizing plans for their events and more and more people are becoming involved in these activities. We all seem to work a little smoother and more effectively as the work load is distributed among many.

With the arrival of spring comes more sunlight and that too is greatly appreciated.

We have lost some very dear friends lately. John, Fred, and Bert gave encouragement to us in our early days and their passing casts a shadow on our hearts. But as they leave, new friends enter our lives, so we take a deep breath and go on.

I'm looking out the window hoping to see a robin before the phone rings and the routine resumes... **June**

WE'LL SET A PLACE FOR YOU...



LUNCH SERVED EVERY DAY

Monday thru Friday 12:00 PM - 1:30 PM

The Living Room North

377 Cumberland Avenue Portland, Me. 04101

Phone: 207-773-8500

OUR WISH LIST UPDATE

From time to time we like to publish our "Wish List Update". These are items that are not normally donated, but would inhance the day-to-day operations of the Coalition.

In this issue we have also included a few items that we think would be appreciated by the people we serve, and would improve their quality of living.

Here's our update:

Camera/Camcorder Carpenters/Helpers Ceiling Fixtures/Fans Cleaning Equipment Cleaning Volunteers Clothing Darkroom Equipment Dining Tables/Chairs Easel/Post Up Boards Fax Machine Food Items Home Meal Program/With Delivery Intercom System Laser Printer Medical Transportaion Service New Furniture for the Living Space **New Living Room Window Treatments Rent Free Space Rich Benefactors** Second Hand Furniture for PWA's Silk Screening Equipment Single Line Telephones Stoves/Microwave Ovens VAN FOR TRANSPORTATION

If you have any, or all of the items listed, call us at the PWA Coalition; 207-773-8500 during regular business hours, or, drop in to see us at The Living Room North...377 Cubmerland Avenue, Portland, Me.

THANKS A LOT!!

BIKE FOR HOPE BIKE-A-THON

SATURDAY, APRIL 27,1991

RIDER PLEDGE SHEET

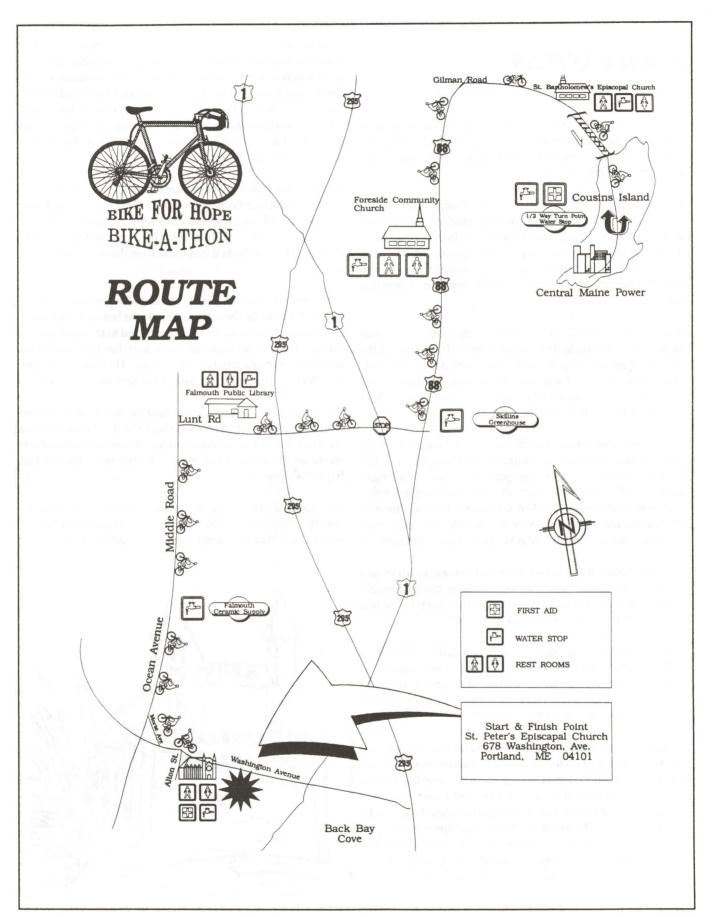
A 27 mile Bike-A-Thon to benefit People Living With AIDS in Maine

CONTRIBUTIONS ARE TAX DEDUCTIBLE
PLEASE PRE-PAY ALL PLEDGES
MAKE CHECKS PAYABLE TO:
BIKE FOR HOPE

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***** You may pledge in any dollar amt. \$1. \$5. \$10. \$15. \$20.



SAND CASTLES

by Eric J. Pepper

My big brother Billy was coming home. It had been three years since the big fight between my dad and Billy. I hadn't understood what happended then and I still have some difficulty with it now.

I remember that night: Mom cried while Dad and Billy yelled at each other. When I got up the next morning, Mom and Dad were talking and crying in the kitchen, still in the clothes from the night before. I got a creepy feeling and decided to keep quiet. Dad told me that Billy had moved out of the house and wouldn't be back. I asked why; no one answered. It was that way for three years.

When Dad mentioned Billy for the first time in three years, that same creepy feeling hit me a second time. I had entered the kitchen, slipped into my usual chair and started to eat my toast. Dad cleared his throat and said, "Son, Billy's coming home for a while." I screamed "HURRAY!," and as I did, Mom ran out of the kitchen. She was crying.

I ran home from school that day and burst through the front door. In the living room was Billy, or who I thought was Billy. He had changed so! The huge guy whose neck I had hung around now seemed small and frail. The guy I used to wrestle with seemed as though he'd break if I hugged him any tighter. Mom came and seemed to have a fit. She told me to go change out of my school clothes. Maybe things hadn't changed.

Dad didn't come home at his usual time from work. Mom said he had to work late. We were all in bed by the time he got home, and when we got up for breakfast the next day he had already left for work. What was going on?

It wasn't until Saturday that I really had a chance to talk with Billy. I quietly knocked on his door and slowly opened it. Billy was sleeping; he was breathing slow and heavy. He looked old, not just a few years older than I. His eyes opened and it was the same old Billy I remembered.

In that same old familiar voice the line came out, "What's up creep?" I was at a loss for words, but I walked over to the bed and sat down. Billy started talking about when he had left, he told me he had wanted to say bood-bye but hadn't been able to. He and Dad couldn't see eye to eye on some things, so he had moved out. He would not have come home but now he was sick, very very sick. I asked him if he would get better and he said no. That's when he said it. "I'm going to die."

With that we both began to cry; he because of fear, me out of love. He went on. He told me he had AIDS and that right now there was no cure. That was why he had lost so much weight and looked so sick. That was why Dad and Mom had let him come home, to die. I just sat there; I didn't know what to say. I thought I was going to be sick. I ran out of the house and got on my bike. I rode till I couldn't breath; and then I cried till I couldn't cry any more.

"Everybody seemed to be walking on egg shells, so I walked lightly, too. Over the next month, Dad started to be at home more and to talk with Billy once in a while. Mom had returned to her usual routines. Bily worried me. He spent a lot of time resting. He went to bed early and took three or four naps a day.

When Summer rolled around, I talked Mom into taking Billy and me down to the shore for a day. On the beach, Billy looked even sicker. He seemed so pale compared to the other tanned bodies. His arms and legs were thin, as if they had no muscles to them. I noticed tiny bruises on him. He wore shorts and a T-shirt. "Too skinny to wear a bathing suit," he said.

We decided to build sand castles near the water. Billy started with his thick outer walls and four high towers. I started nearer the water with a moat and drawbridge. When we had finished, we sat and admired our creations. By this time, the tide had begun to come in.

We watched the hands of nature wipe the beach clean. Quietly, Billy spoke, "We all have ways to protect ourselves like walls; either by yelling, ignoring, running away...



Continued to Page 9

Sometimes the walls don't help, especially when the thing we are afraid of is something we can't control. Instead of making us stronger, it tears us down." At this point the waves had washed away my draw bridge and caused my fortress to crumble. Standing alone was Billy's castle which would soon be gone too.

I felt alone and scared all of a sudden. I moved closer to my brother, and he put his arm around me. We sat silently and watched as the ebb and flow of the tide crept higher up the beach. The waves started to slowly attack Billy's castle.

I turned to my brother and said, "Billy, I don't want you to die." He said, "I don't want to die either, but right now people with AIDS don't get better.

Together we watched as the water leveled the beach where Bill's castle had been. I couldn't hold back the tears that were running down my cheeks. I didn't want Billy to see them, but he already had. He pulled me closer and gave me a hug. He knew I was thinking about him and death.

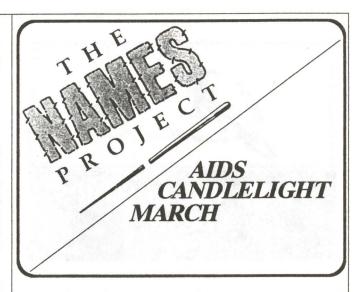
Billy slowly began to talk, "I'm not really going to be gone; I'll always be near you. Look over there..." He pointed to where the sand castles had been.

"The castles are not gone. They have only changed form. Every bit of sand that made them up is like a memory...all you have to do is put them together again..."

Now I go to the beach by myself. Each summer I build a big sand castle near the water's edge with thick walls and four high towers. And while I build I think of Billy and our last day at the beach. Then I sit back and watch the tide creep up the beach, knowing that Billy is sitting there beside me



Members of the writing staff wish to thank The PWA Coalition of New York for their permission to re-print the article on Vitamin C and the "Sand Castles" article which originally appeared in the January/February 1991 issue of their newsletter.



May 19, 1991

The Names Project/Maine, The AIDS Project, and The People with AIDS Coalition of Maine will jointly sponsor a candlelight march, and memorial gathering on Sunday, May 19, 1991.

This Event will commenorate the 8th annual International AIDS Candlelight Memorial.

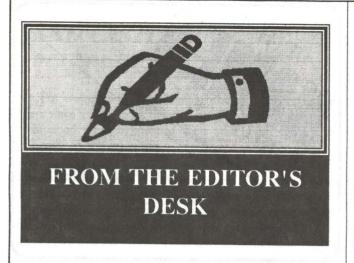
The candlelight march will start on Monument Square in Portland at 6:00 PM. Participants will march to St. Luke's Cathedral on State Street where there will be an interfaith memorial gathering beginning at appoximately 6:30 PM, featuring guest speakers and soloists to celebrate the lives of those who have died of AIDS.

This is Portland's 6th year to participate in this worldwide memorial, united in remembrance, hope, and action. There will also be a candlelight memorial in Bangor, Maine, sponsored by the Downeast AIDS Ntwork.

The public is encouraged to participate. Questions should be directed to David Ketchum; 207-934-4997, The AIDS Project:; 207-774-6877, or to The People With AIDS Coalition; 207-773-8500.

The memorial gathering will be interpreted for the hearing impared.

KEEP THE LOVE ALIVE



Commitment to volunteer time to any organization takes a lot of forethought, more than just realigning your time to make it possible. In the case of The PWA Coalition it took a bit more than just commitment for me. It meant coming to grips with a long time battle to admit that things have changed in my life and will never be the same.

After five years of diagnosis, treatment, and counseling I must look AIDS in the face every day. I realize that it isn't going to go away. I must say that it is no easier to accept today than it was five years ago. And most days the way that I react to situations seems to be no better than five years ago. Yet the long days, months, and now years, of dealing with this issue has dictated that I decide who best could get the job done of improving the quality of my life.

It has been my experience that governmental agencies are not the best ones to handle the job. Most agencies in Maine, as well as most states, do not have the experience nor the enthusiasm to guide a person with HIV through the maze of agencies that, in the end, can provide a better quality of life.

The PWA Coalition in Portland has taken upon itself to help it's clients through the tough times. It's Board members and volunteers are doing their best to provide programs, and furnish information to reduce the amount of stress this disease carries along with it. Programs that provide food, lunchtime meals, small household items, clothing, referrals to resource programs available, and a safe place for people with HIV to meet are but a few of it's programs.

In the next couple of months several programs to raise funds are planned. These programs provide the cash needed to keep the Coalition's going forward. In the case of the Bike-A-Thon, some of these can be fun, at the same time raise much needed funds. But no matter, whether fun or more serious, each event is essential to our continued growth.

This is my first chance to edit and publish The Scoop. I hope hope that the information we share with you is interesting, informative, and even fun, and that you'll choose to share your talents with the talents of the many volunteers at The PWA Coalition of Maine... **Thom Alan**

NEWSLETTER SUBSCRIPTION

The Scoop is Published by The People With AIDS Coalition of Maine. The newsletter is offered to any individual, business, school, church or other interested parties free of charge. It is important that we have your full and complete address to insure that you receive each issue. The U.S. Postal Service will not forward or correct any name/address changes, nor will they deliver mail with incorrect information. Please keep us informed of any changes by mailing the form below.

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A SPECIAL THANK YOU

On Wednesday January 30th, we shared the Phyllis Thaxter Theater with The Zonta Group, for a performance of Nunsense. The evening was a tremendous success. All who attended had a wonderful evening.

My special thanks to all those who supported us on our first theater outing... Chuck Sawyer

April 1991 PWA COALITION OF MAINE

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
	5:15pm SIGNIFICA- NT OTHERS SUPPORT GROUP	8:00pm POSITIVLY SOBER AA MEETING	6:00pm DINNER 7:00pm EXECUTIVE BOARD OF DIRECTORS MEETING	12:00pm TAP LUNCH FOR PWA'S AND THEIR FRIENDS	5	6
7	8 5:15pm SIGNIFICA- NT OTHERS SUPPORT GROUP	9 8:00pm POSITIVLY SOBER AA MEETING	10 6:00pm DINNER 9:00pm NEWS PAPER ARTICLE DEADLINE	11 12:00pm TAP LUNCH FOR PWA'S AND THEIR FRIENDS	12	13 10:00am COALITION GROUP WORK PROJECT
QUILT WORK- SHOP 6;30pm BRIDGES CHOIR REHEARSAL	5:15pm SIGNIFICA- NT OTHERS SUPPORT GROUP	16 8:00pm POSITIVLY SOBER AA MEETING	17 6:00pm DINNER 7:00pm BOARD OF DIRECTORS MEETING	18 12:00pm TAP LUNCH FOR PWA'S AND THEIR FRIENDS	19	20
21	5:15pm SIGNIFICA- NT OTHERS SUPPORT GROUP	23 8:00pm POSITIVLY SOBER AA MEETING	24 6:00pm DINNER	25 12:00pm TAP LUNCH FOR PWA'S AND THEIR FRIENDS	26	27 10:00am BIKE FOR HOPE BIKE-A- THON
QUILT WORK- SHOP COMEDY CAN CAN LIMELIGHT	5:15pm SIGNIFICA- NT OTHERS SUPPORT GROUP	8:00pm POSITIVLY SOBER AA MEETING	NAPWA NORTHEAST CONFERENCE PORTLAND, MAINE MAY 17 THRU MAY 19,1991 FOR ALL PEOPLE WITH HIV CALL TO RESERVE SPACE			

April 1991

TLRN 377 CUMBERLAND AVENUE PORTLAND, ME 04101

ADDRESS CORRECTION REQUESTED

