

ANAC
ASSOCIATION OF
NURSES IN AIDS CARE

Newsletter of the HIV-Positive Nursing Committee Volume 4 Number 4 Fall Issue 2003

#### In this issue...

- Letter from the Editor...
- Entry Inhibitors:
   A New Class of Drugs to Treat
   HIV Infection
- HIV and Lactation
- Assessing HIV+
   Women for Vulvar,
   Vaginal
   Intraepithelial
   Neoplasia
- Loving Yourself

The purpose of life is to matter-to count, to stand for something, to have it make some difference that we all lived. (Leo Rosten)

# Letter from the Editor...

Wow - I can hardly believe that +Nurse is now 3 years old. It seems like only yesterday that the HIV Positive Nursing Committee, of the Association of Nurses in AIDS Care (ANAC), was discussing the expansion of our outreach program in an effort to establish a supportive network for HIV-positive nurses. One of the main goals of the HIV Positive Nursing Committee is to reach out to all HIV positive nurses, regardless of practice setting or organizational affiliation. One way to do this was through a newsletter - thus +Nurse was born.

Over the course of the last 3 years +Nurse has been a voice through which HIV positive nurses can share their stories, questions, experience, and expertise. I have been so deeply moved as many have bared their souls and opened their hearts with such honesty and emotion, that tears just naturally flowed as I read the accountings of my fellow sojourners. Stories mingled with tragedy, but masterpieces of triumph.

As co-editor of +Nurse I am also afforded the wonderful opportunity of being able to communicate nationally and internationally with HIV positive nurses. Technology affords us the wonderful opportunity of communicating via email, and I consider it a distinct honor and privilege to provide you with advice and words of encouragement. Please feel free to use my email address to contact me if you would like to contribute an article to +Nurse.

Never underestimate the impact that you can have on other people. I cannot tell you how many times I hear from people saying, "We came across +Nurse online and have found it so helpful." If you have a question about something let us know. Positive Nurse is committed to remaining a voice for the HIV positive nurse.

Treasure yourself,

David J. Sterken david.sterken@spectrum-health.org

## Entry Inhibitors: A New Class of Drugs to Treat HIV Infection

Richard S. Ferri, PhD, ANP, ACRN, FAAN

The first fusion inhibitor, T-20 or Fuzeon (Fuzeon®; Roche), approved by the US FDA on March 15, 2003, heralds an era in which new viral targets are used to suppress viral replication, potentially reducing long-term toxicities and avoiding cross-resistance with currently available antiretrovirals (AVRs).

Fusion inhibitors are aiming at new targets involving the prevention of initial viral entry into the cell have been explored at three distinct steps of viruscell interaction; binding of the viral envelope protein gp120 to the CD4(+) receptor molecule on the cell surface; binding of the viral envelope to the chemokine co-receptor molecule; and fusion of the viral and cellular membranes.

## What are in clinical indications for the use of Fuzeon?

Fuzeon in combination with other antiretroviral agents is indicated for the treatment of HIV-1 infection in treatment-experienced patients with evidence of HIV-1 replication despite ongoing antiretroviral therapy. In other words it is not a first line agent and is presently reserved for "salvage" therapy.

#### What is the dose of Fuzeon?

In adult patients the dose of Fuzeon is 90 mg twice daily by subcutaneous injection. In the pediatric population from age 6 to 16 years the approved does is 2.0 mg/kg twice daily up to a maximum dose of 90 mg twice daily.

Injection sites should be routinely rotated to prevent injection site reactions (ISRs). About 9% of patients developed ISRs that resulted in the need for analgesia or limited activities of daily living.

Continued from page 1

Manifestations may include pain and discomfort, induration, erythema, nodules and cysts, pruritus, and ecchymosis.

There are several essential teaching points that nurses need to convey to their patients.

- 1. Fuzeon is administered by subcutaneous injection only. It should never be administered intravenously or intramuscularly.
- 2. Both daily doses of Fuzeon can be reconstituted at the same time with the second dose stored in the refrigerator in the vial. Fuzeon should never be stored pre-mixed in a syringe.
- 3. After instilling the sterile water for reconstitution NEVER shake the vial since this will INCREASE the amount of time for reconstitution.
- 4. Fuzeon may be gently rolled between the hands to assist with drug reconstitution.
- 5. Prescriptions for Fuzeon need to be called in, mailed, or faxed to Roche and are processed on a first-come, first-served basis. Prescriptions are filled and shipped to patients (or their healthcare providers) by a single pharmacy: Chronimed/StatScript. For more information on filing prescriptions please call the toll-free number: 1-866-694-6670.

#### Fuzeon Research Update

Some new promising research and data were presented at the International AIDS Society (IAS) meeting in Paris this past spring. Efficacy data established at 24 weeks was found to be intact at week forty-eight.

At baseline, patients had a median HIV level of over 5 log<sub>10</sub> copies/mL and extensive prior exposure to multiple anti-HIV drugs. At 48 weeks, patients who received Fuzeon as part of their individualized regimen achieved a mean reduction in HIV levels of 1.48 log<sub>10</sub> copies/mL compared to a mean reduction of 0.63 log<sub>10</sub> copies/mL for those randomized to an individualized regimen without Fuzeon. The difference in the scale of the decrease in HIV between the two arms at 48 weeks was 0.85 log<sub>10</sub> copies/mL.

You are here for a purpose. There is no duplicate of you in the whole world. There never has been, there never will be. You were brought here and now to fill a certain need. Take time to think that over. (Lou Austin)

#### Quality of Life

Also at the IAS Conference, Cohen, et al. showed that patients receiving Fuzeon plus an optimized background regimen had statistically significant improvements in quality-of-life scores compared to baseline. In contrast, patients in the control group not receiving Fuzeon, but taking an optimized background regimen only, did not have significant improvements in quality-of-life scores

For more information on Fuzeon and patient support programs please visit www.fuzeon.com.

#### References:

Battegay M, et al. Analysis of virological failure through 24 weeks of treatment in the TORO pivotal studies. Program and Abstracts of the 2nd International Conference on HIV Pathogenesis and Treatment, July 13-16, 2003, Paris, France. Available online at: www.ias2003.org/. [Abstract 574]

Cohen C, et al. Impact of Fuzeon on health-related quality of life. Program and Abstracts of the 2nd International Conference on HIV Pathogenesis and Treatment, July 13-16, 2003, Paris, France. Available online at: www.ias2003.org/. [Abstract 1148]

### **HIV and Lactation**

Thom Thiele, ACRN, IBCLC

From the early '80's to the present date the "Faces of AIDS" has changed dramatically. At the end of '94 we saw Men Who Have Sex with Men (MSM) go under 50% of the total number involving AIDS cases with the U.S. The number of AIDS cases worldwide has always shown a majority being heterosexual. This country has been unique in its presentation of the epidemic.

As the epidemic evolved into the mid '90's we found that HIV was currently the fourth leading cause of death among women between the ages of 25 & 44 years of age. This represents the portion of the population that shows the fastest growing area of new cases in the U.S.

As we headed into the new millennium we as caregivers were finding ourselves

exposed to more women in the OB/GYN division of hospitals who were HIV positive who were questioning the feasibility of breast feeding. We, as their caregivers, have found ourselves faced with ethical, moral and personal prejudices that may affect our deliverance of care to this very unique hospital population. It is not within our realm of care to judge why these women have come to us with these health challenges (HIV) and desires (to breast-feed). If we allow ourselves to judge we merely revert back to the early '80's when so many of the (MSM) found such attitudes directed toward them upon their hospital admissions. For whatever reasons: An infidel significant other, an occupational skin puncture, the hope of producing a healthy baby as a result of the premature enthusiasm over the success of new drug therapies, etc., this patient population has the right to dignity and professionally sound advice concerning their health and the desire to breast feed.

Should HIV positive women breastfeed? Much to you surprise, I am sure, the answer is NOT a strongly stated NO. There are several schools of thought here. The first is to question whether the HIV positive mother is within an industrialized or third world country. It is standard medical practice to advise HIV+ women living in developed countries (with a safe water supply and sanitation system) not to breast-feed. In under developed countries an estimated death toll to HIV infection through breastfeeding could between 1,000 and 19,000. By contrast, deaths due to diseases of infancy caused by not breastfeeding would range from 10,000 to 75,000 in a year's time. The median incubation time for developing AIDS for bottle fed children is 9.7 months, while for breast fed children is 19.0 months. This statement promotes the theory that a baby born in an under developed country without the access to infant vaccines will die sooner of diseases of infancy than from AIDS.

One of the most exciting breakthroughs involving the AIDS epidemic in the year 1994 was the discovery that administration of AZT to pregnant women decreased the vertical transmission (from mother to child) from 28 - 30% down to 8%. Over the past 7 years that percentage has down between 6 to 1%. With these results clearly documented one would ask why ever you would want to jeopardize infecting a baby post delivery when such odds as stated above have

been overcome. Of course this situation is specific for industrialized nations - those that have the financial ability to provide the necessary drug therapy to accomplish such goals.

Another argument, which has presented itself, involves the process of pasteurization. The actual definition is the exposure of milk to a temperature of 60 degrees C (140 degrees F) for 30 minutes. The Human Milk Banking Association of North America in consultation with the FDA suggests that a temperature of 56 degrees C is effective in killing bacteria along with the HIV virus. The form of pasteurization is known as Holder Pasteurization. If the boiling point of water is 100 degrees C (212 degrees F) the process of pasteurization would be more than sufficient to purify breast milk from viral components. Unfortunately, it would also destroy all of the immune qualities of mother's milk for the baby to benefit from. Due to the lack of research in this area it would be reckless to suggest home boiling of mechanically pumped breast milk with the hopes of feeding it to an infant.

Because of the advent of this most unique challenge in the area of caregiving, new ideas of research have presented themselves that could benefit the future welfare of babies born of HIV+ mothers. Issues such as this need to be brought into awareness before an interest and therefore research producing an end result can be hoped for.

In response to the question "Can an HIV+ mother breast feed?," there is not a clear cut answer. With further awareness to this subject and a non judgmental approach to this issue, it may be possible in the future for babies of HIV infected mothers to benefit from that wonderful substance we call human breast milk.

REFERENCES TO "HIV AND LACTATION"

The Washington Post, 7/30/95, pg. A27 (Reference from U.S.CDC)

World Health Organization, Wkly Epidem Rec, No. 33, 8/14/87

NNWRm 8/5/94m /vik, 43/No. RR-11

Breastfeeding and Human Lactation, 1993, pg. 167, Col. 2

Continued on page 4

Change and growth take place when a person has risked himself, and dares to become involved in experimenting with his own life. (Herbet Otto)

B & HL, 1993, pg. 168, Col 2

WHO/UNIFEF: Breastfeeding in the '90's: Review and Implications for a Global Strategy, Technical meeting, Geneva, 6/25-28/90

New Eng J of Med, 5/8/97, Vol. 336, No. 19, pg. 1337-1342

SF AIDS Fdn: BETA, 4/99: Recent News about Women & HIV

Limpongsanurah, S. et al. Safety, Tolerability & Efficancy of Ritonavir in the Prevention of Vertical Transmission, 6th CROL, Abstract 241

Thiele, T., HIV/AIDS: Past to Present, "Breastfeeding: Lactation Consultants Protecting a Renewable Resource, 1998 Annual ILCA Conference, Boca Raton, Fl., July 15-19, 1998

Thiele, T., Breastfeeding '99 - The Vital Gift, Third Annual North American Conference, "HIV and Lactation to the Present Date", March 5-7, 1999

## Assessing HIV+ Women for Vulvar, Vaginal Intraepithelial Neoplasia

Thom Thiele, ACRN, IBCLC

Vulvar and vaginal intraepithelial neoplasia are not uncommon in women with HIV infection. They will often develop these two neoplasia along with high-grade cervical lesions which is an excellent reason for assessing infected women. HIV+ women should be exposed to colposcopy and vulvoscopy as essential diagnostic tools.

Studies involving HIV+ women have shown development of high-grade vulvar or vaginal lesions. CD4 counts with these women were compared with those in an age-matched group (19-69 years of age) who either had cervical intraepithelial neoplasia without vaginal or vulvar involvement or who had no human papillomavirus infection. It was discovered that the lower the CD4 counts, the higher risk of developing one or both of the neoplasia. Multifocal lesions were noted in women with an average CD4 count of 233 compared to women with CD4 counts averaging 386.

Those women with counts averaging 452 had only cervical lesions and who were negative for any human papillomavirus.

**Reference:** Mary Ann Moon; Ob.Gyn.News, September 1, 2003, page 14a, column 1

### **Loving Yourself**

David J. Sterken MN, CNS, CPNP

I would like to offer you some inspirational thoughts for your journey. These words come from the book - The Power is Within You - by Louise L. Hay. Personally I have discovered that loving myself is an "adventure" as well as an "inventure". Louise Hay describes 10 Ways to Love Yourself

#### Stop criticizing yourself.

We are all insecure in some ways because we are human. Let us not pretend that we are perfect...Instead, we could discover our creative distinctions, our individualities, and appreciate ourselves for the qualities that set us apart from others. Each of us has a unique role to play on this earth, and when we are critical of ourselves, we obscure it.

#### **Stop scaring yourself.**

Many of us terrorize ourselves with frightful thoughts and make situations worse than they are. It is a terrible way to live, always expecting the worst out of life.

## Be gentle and kind and patient with yourself.

Impatience is a resistance to learning. We want the answers without learning the lessons or doing the steps that are necessary. It is okay to make mistakes while you are learning. Anything you are going to learn takes time...Mistakes are your stepping stones.

#### Learn to be kind to our minds.

Let's not hate ourselves for having negative thoughts. We can think of our thoughts as building us up rather than beating us up. We don't have to blame ourselves for negative experiences. We can learn from these experiences. Being kind to ourselves means we stop all blame, all guilt, all punishment, and all pain.

If you are never scared or embarrassed or hurt, it means you never take chances.
(Julia Soul)

Continued from page 4

#### Praise yourself.

Criticism breaks down the inner spirit, and praise builds it up... The next time you do something new, or different, or something you are just learning and you're not too adept at it, be there for yourself.

## Loving yourself means supporting vourself.

Reach out to friends and allow them to help you. You really are being strong when you ask for help when you need it.

#### Love your negatives.

They are all part of your creation...No matter what negative situation you are in, it's there for a reason; otherwise you wouldn't have it in your life.

#### Take care of your body.

Think of it as a marvelous house in which you live.

Even a happy life cannot be without a measure of darkness, and the word "happiness" would lose its meaning it is were not balanced by sadness.
(Carl Jung)

# Contact us

One of the main goals of the HIV-Positive Nursing Committee and + **Nurse** is to reach out to all HIV-Positive nurses, regardless of practice setting or organizational affiliation. You do not have to be a member of ANAC or an AIDS nurse to benefit from +Nurse.

You can contact us at + Nurse, c/o Association of Nurses in AIDS Care, 3538 Ridgewood Road, Akron, Ohio 44333,

Phone: 330-670-0101 or 1-800-260-6780;

Fax: 330-670-0109

E-Mail: anac@anacnet.org; Web Site: http://www.anacnet.org

Co-Editors

David J. Sterken, MN, CNS, CPNP
Richard S. Ferri, PhD, ANP, ACRN, FAAN
Editorial Reviewers
Alton Burch, RN, ACRN
Cheryl Erichsen, LPN
Richard MacIntyre, PhD, RN

Robert Thompson, RN, CRNI

We achieve a sense of self from what we do for ourselves and how we develop our capacities. If all our efforts have gone into developing others, you're bound to feel empty.
TAKE YOUR
TURN NOW.
(Robin Norwood)

#### Mirror work.

You can talk to other people in the mirror, especially when you are afraid to talk to them in person. When we won't forgive, when you won't let go, we're binding ourselves to the past, and when we are stuck in the past, we cannot live in the present time, and if you are not living in the present, how can we create our glorious future. Old garbage from the past just creates more garbage for the future.

#### Love yourself now.

Dissatisfaction with yourself is a habit pattern...We can't change other people, so leave them alone. You can't learn life from another person. Everyone has to learn his or her particular lessons...When you leave the planet the only thing you take is your capacity to love.

We as a committee would love to hear from you. Do you have ideas for articles? We would welcome anyone who would like to submit an article. Deadline for our next publication date is February 4, 2004. Let us know if you are interested in writing an article.