This month we are fortunate to have a guest columnist, Jay Elbrecht, MSW, Social Worker at the HIV Day Center.

**Trans Health:**

Research to date has largely ignored the impact of HIV on the "gender community": transsexual, transgendered. Several small studies in Atlanta, San Francisco, and Minnesota have been analyzed together finding that transgendered sex workers were 68% more likely to have HIV exposure than their non-gender variant sex worker counterparts. A San Francisco clinic found that 15% of transgendered individuals seeking hormone treatment were infected with the HIV virus. Future evidence from these studies suggest that, low socioeconomic status, social isolation, low self-esteem, and psychosocial factors is what researchers state as probable factors to HIV exposure.

Even less is known regarding persons who experience gender identification elsewhere on the theoretical continuum, such as those who exhibit a gender-blended self-perception. In addition, most HIV-related services, both preventive and supportive, do not include "T-friendly" assessment and/or support. Misperceptions regarding members of the gender community also cause difficulties for persons with non-traditional gender identities seeking healthcare, resulting in delays in entering the healthcare system and the provision of inappropriate services after contact has been made. Because of the social invisibility of the gender community, reports of medical mistreatment reach the media only when breaches of medical ethics are most glaring, such as the case of Tyra Hunter, who died following an assault in 1995. (She had been refused care by the responding emergency services personnel who believed, due to her transsexualism, that she had AIDS.)

Despite the lack of research regarding HIV in the gender community and the paucity of outreach to this population, pilot projects, such as that sponsored by the University of Minnesota, have shown that the many members of the gender community are at high risk for HIV/AIDS, and that culturally-appropriate educational interventions are needed. The biggest risks for infection stem from the combination of lack of appropriate information regarding HIV prevention in the gender variant community, which particularly affect the gender community dependent on prostitution and/or "survival sex" for income following the loss of employment during gender transition process, and, due to lack of economic resources, often many must rely on non-prescription obtained hormones and silicone preparations and non-sterile injection equipment. Research has revealed that the majority of male-to-female (MTF) transgenders and transsexuals present for medical gender transition services after the age of 40, FTMs have often resolved their gender identity issues at younger ages, in addition, gender identity is often somewhat fluid at earlier ages, and is best represented along a continuum. For persons in a more secure economic setting relative risks of sexual activity following sex-reassignment surgery and the emotional consequences of beginning sexual experimentation in one’s true gender at older ages (which often result in risk-taking behavior, i.e. the "fifty year-old adolescent"). Presentations need to be developed to familiarize healthcare workers and HIV advocates with the dynamics of HIV infection and treatment issues in the gender community, and there is a need to develop presentational clinical tools for outreach and service providers to this invisible population.

1. HIV Prevention and Health Service Needs of the Transgender Community in San Francisco: by Kristen Clements, MPH; Willy Wilkinson; Kerily Kitano, PhD; Rani Marx, PhD MPH
6. The nine point gender continuum: Results from the University of Michigan Medical Center Comprehensive Gender Services Program Longitudinal Transgender Health Project: By AE Eyler MD, Sandra Cole PhD, Kathryn Wright DO, TM Witten PhD University of Michigan Medical center Comprehensive Gender Services Program.
After a wait of over five years, Social Security (SSA) has issued revisions in April to the regulations that cover all immune disorders. These include inflammatory arthritis, lupus, scleroderma, connective tissue disorders, HIV and AIDS, polymyositis and dermatomyositis, and a new Sjogren’s syndrome listing.

The finished regulations are the result of much work within the agency in consultation with their own and other medical experts. Numerous autoimmune advocacy groups had extensive input, and there was a process for public comment through the Federal Register. Two town hall meetings were held nationally. Nothing happens quickly in this regulatory world, but this was exceptionally deliberate and slow, for good reason. The changes have been extensive philosophically.

There have been wide-ranging improvements in treatment and diagnosis modalities for all these autoimmune disorders, and the agency has recognized these. The one exception to the final regulation is the HIV Listing, which had an additional comment period. The HIV Listing was created in 2003 and has not been changed since. The treatments for this illness alone have changed and evolve daily. Fitting that dynamism into a static regulation is a real job.

SSA has used the success of structure of the HIV listings’ unique measurements and applied it to these other syndromes. These measures include “manifestations” of the illness that are repeated and recurring rather than constant. They also include considering the effects of cumulative treatment that are debilitating – for example, interferon treatment for Hepatitis C in a person with AIDS. The interactive effects of treatment, and the side-effects such as impairment of memory, mood, concentration and energy level are now considered.

SSA now also includes functional criteria in a way that weights this more strongly. Again in the case of HIV, no longer will CD4 counts be the definitive measure – the adjudicator will have to look at the person’s capacity to function and fatigue levels - not just at a test result number. A case will not be denied simply because a lab value has gone up or down. SSA says that these autoimmune disorders can be “invisible,” and “objective markers are not obvious” and can’t be easily described.

Lastly, SSA has removed the linkages to other in the former regulation. Previously many conditions simply referred to other body systems’ regulations – for example, was the claimant depressed enough to meet the standards set forth in the mental impairment sections of the law. Now these conclusions can be made within this new regulation, considering these as measurable manifestations of the various autoimmune disorders.

The proof is in how workable the regulations turn out to be. It is heartening that SSA took the positive experience of the structure of the HIV regulations, the result of strong advocacy from passionate interest groups in the early 90’s, and applied it more broadly. The result could be more meaningful decisions at earlier stages of application.
I’m about to start taking meds for the first time; my T-cells are 249 and my viral load is 110,000. The doctor has explained to me that the goal for my viral load is to go down to less than 50 by 4 to 6 months. What is my CD4 count going to do? Will it go up? How high?

After starting meds, the effects on CD4 count are not as easy to predict, there is more variability. Most people find that the count rises after starting meds, this is called an immunologic response. Numerous studies have been done over the years to help answer this question though earlier studies may not be applicable to the potent ARV therapy we use in this era.

The EuroSIDA cohort, which is a European study of over 14,000 patients with HIV infection in Europe, Israel, and Argentina, has been collecting data from as early as 1994. A subgroup of 1835 antiretroviral-naïve patients participated in a sub-study to follow increases in CD4 counts after starting meds. Patients were included if they had at least 2 consecutive HIV viral loads < 50. CD4+ cell counts were obtained before starting meds and every 6 months thereafter. Regimens included PI based, NNRTI, and triple NRTI (<15%)

<table>
<thead>
<tr>
<th>Starting CD4+ Count</th>
<th>Years on meds</th>
<th>CD4+ Increase per Year</th>
<th>Current CD4+ Count</th>
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<td>76</td>
<td>204</td>
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<td>69</td>
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The average CD4+ count at initiation of ARV was 204 (range 91 to 340) in this study. The greatest increase was observed in the first year after starting meds, averaging about 100 regardless of CD4 count when meds were initiated. The majority of patients continued to experience rises of CD4 even after 5 years, the exception being those who current CD4+ count > 500. Multivariate analysis showed no significant effect on the yearly increase in CD4 cell count based on age, change in CD4+ cell count since starting HAART, the peak HIV viral load or CD4+ cell count at baseline.

Other studies have shown similar trends, however, others have suggested a plateau with no further increases after 4 years. Continued viral suppression, to less than 50, may have been a factor in the results of the EuroSIDA study. Also, CD4 count was not further stratified below 200, use caution about applying to very low baseline CD4 counts. There is a subset of patients, who despite virologic suppression do not see the CD4 increases demonstrated above. More research needs to be done in this area.

COMINGS AND GOINGS

At CAP, Amanda Hurley has been promoted to a team lead in the Supportive Housing and Care Services Department. Donna Standing Rock is now a housing case manager working on the SPNS grant for clients transitioning out of corrections. Salvador Candela, a long time employee of CAP, has moved back to Mexico.

HELP YOUR MOM SAVE $3,600!

By Alan Edwards, Social Security Public Affairs in Oregon

People all over the country are helping their moms save as much as $3,600 per year on the cost of prescription drugs. You can too! We all know the high cost of medicine can be a burden on mothers who have limited income and resources. But there is extra help — available through Social Security — that could pay part of her monthly premiums, annual deductibles and prescription co-payments. The extra help could be worth up of $3,600 per year.

To figure out whether your mother is eligible, Social Security needs to know her income and the value of her savings, investments and real estate (other than the home she lives in). To qualify for the extra help, she must be receiving Medicare and also have:

Income limited to $15,600 for an individual or $21,000 for a married couple living together. Even if her annual income is higher, she still may be able to get some help with monthly premiums, annual deductibles and prescription co-payments. Some examples where income may be higher include if she or her spouse:

—Support other family members who live with them;
—Have earnings from work; or
—Live in Alaska or Hawaii; and

Resources limited to $11,990 for an individual or $23,970 for a married couple living together. Resources include such things as bank accounts, stocks and bonds. We do not count her house and car as resources.

Social Security has an easy-to-use online application that you can help complete for your mom. You can find it at www.socialsecurity.gov. To apply by phone or have an application mailed to you, call Social Security at 1-800-772-1213 (TTY 1-800-325-0778) and ask for the Application for Help with Medicare Prescription Drug Plan Costs (SSA-1020). Or go to the nearest Social Security office.

To learn more about the Medicare prescription drug plans and special enrollment periods, visit www.medicare.gov or call 1-800-MEDICARE (1-800-633-4227; TTY 1-877-486-2048).

So this Mother’s Day, help your mom save up to $3,600 a year on her prescription drugs. Long after the candy and flowers are gone, the extra help through Social Security will keep on giving.