Letters—December 2013

November 11, 2013

Survivors Speak
The article "Older and Wiser" (September 2013), by Tim Murphy, explored issues surrounding long-term survivors of HIV and the difficulties they often face.

This article almost made me cry. I'm 50 years old and have been positive more than half my life. I feel like I'm a relic from a long ago time and just don't fit in anymore. I'm glad to know I'm not the only one feeling a bit disconnected. Getting old in our youth-obsessed culture is bad enough, but being positive adds an extra burden.

Tom, Houston

As a long-term survivor myself (diagnosed in 1987), I could certainly relate to much of the article. I was very sick when the protease drugs came out in 1996. My life was saved, but my future was uncertain, and it has been very difficult to find my place in the world. Post-traumatic stress, survivor's guilt and numerous health issues—these are all things I deal with daily. It was nice to be recognized and appreciated in Tim Murphy's piece. I am very fortunate to have a loving partner and caring family and friends.

Alabama

I was diagnosed in 1986, and like many in those days, I was given a maximum of 18 months to live. I'll be 60 this year—imagine that! Going through the plague years in San Francisco is not something that you can just tell someone about and have them believe you. I can so relate to the stories in the article. Hang in as best you can! Not very easy to make friends these days, but knowing others have gone through the same or similar helps a bit.

Jack, Tampa

Thank you for doing a wonderful story. Those of us who have survived HIV (I have for 28 years) do deserve to celebrate! We have come a long way!

Vickie Lynn, Lutz

I can relate to these stories. I'm a long-term survivor and have buried all my friends and my husband. I was recently forced into a retirement due to another damned bout of pneumonia. I am left with the feeling of, "Why am I still here?" Sadly this happens a lot these days. This is not a fun road, but for some reason I am still here. So I will get up each day and keep going. It's all I have left.

Wolf, Tallahassee

It's good to see other long-term survivors. I was infected with HIV when I was 20; I'm now 54. I have always been an AIDS advocate, even to this day serving the rural communities in Florida, where education is still needed. Since I have been blessed with living so long with the virus, I try to give back as much as I can to the community and the state of Florida to show my appreciation for good health and a long life.

George McRae Jr.
Orlando

I'm almost 50 years old, and I've been positive for 27 years. A long time ago, I chose to not let HIV define me. I wear it like a medal of honor. I have suffered with depression but still manage to get up every morning and ask the question, "What new and exciting thing will happen to me today?" I'm married to my partner of 17 years, also positive. Keep learning and socialize outside the gay community. Everywhere in this country there are people who will love you for who you are—you just need to find them.

Andy M, New Jersey

More on Mail Order
The article "Mandating Mail-Order Pharmacies" (September 2013) by Rita Rubin highlighted the ongoing problem of insurance companies requiring the use of mail order for HIV medications.

I have gone to pick up my meds at a pharmacy only to find that they had made a mistake. Being able to correct the situation, right then and there, helps eliminate what could have been a delay in my treatment. In addition, my local pharmacy can ship my meds to me if I am out of town. There's nothing wrong with the way we have been getting our meds, so don't try to "fix" it.

Gregory Veney, Tampa

I have friends that use mail- order pharmacies for all their meds, and they like it very much, but I

don’t think mandating mail-order pharmacies is a good choice. Some of us love having the contact with our pharmacist and consider the pharmacist an essential part of our health care.

Larry Frampton, Knoxville

I am currently in this fight with Anthem Blue Cross/Blue Shield and OptumRX. I am furious and am in contact with my employer’s benefits administrator. She had no idea of any potential problems. I am healthy, but I fear the delays, screwups and downright incompetence of these pill mills.

Arj, Ohio

Funny, I have just the opposite problem. I would love to get my meds via mail, but I use ADAP, which pays my prescription co-pays, and I’m forced to drive down to Kaiser’s pharmacy every month to pick up my meds. The ADAP provider won’t allow mail order for some reason, and it’s a major inconvenience.

Squeaker, San Diego

What the hell? Like I don’t already have enough to worry about. I get my meds from a pharmacy that is in the lobby of the clinic I go to. I will be getting ahold of them now to make sure this crap is not going to happen to anyone I know (myself included). After 23 years of this fight, I don’t need this headache!

Doug S, Boston

[Getting meds through mail order] has been such a source of frustration. I’ve never missed as many doses as I have now—and it’s because I can no longer go down to the corner and pick up my refills. All so that United Healthcare can make more money. Profit over health is seriously f*cked up.

RJB, New York

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