

TO: The Commonwealth of Massachusetts
Joint Committee on Public Health
Senator Susan C. Fargo, Senate Chair
Representative Jeffrey Sanchez, House Chair
and Committee members

FROM: Ed Perlmutter

RE: Written Testimony in Support of S. 821

Chairwoman Fargo, Chairman Sanchez, and members of the Committee,

Please accept this written testimony based on oral testimony I delivered to the Committee at the October 6, 2009, hearing. You may contact me directly with any questions or concerns regarding my testimony. I want to extend my sincere thanks to the Committee for allowing me to speak that day, and now in writing, in support of Senate Bill 821.

My name is Ed Perlmutter. I live in Brighton, I am 48 years old, and until I testified before the Joint Committee on Public Health on October 6, only a handful of people in the world knew that I was HIV-positive. My family did not know. My work colleagues did not know. Virtually all of my friends did not know. Nevertheless, I came before the Committee because I believe so fervently that had routine opt-out HIV testing existed in Massachusetts in 2005, I would have learned my status earlier and been able to begin treatment sooner. I was both humbled and terrified to share with you my story that day, and was honored to be in the company of the broad-based coalition that came together to explain why eliminating written informed consent, and adopting routine opt-out HIV testing, is a change that is long overdue in Massachusetts.

While I can speak only to my experience, my experience is unfortunately not unique. And so I write to you now on behalf of the most important coalition of all -- the thousands of residents of the Commonwealth who are infected with HIV but who don't know it because they have not yet been tested. It is these individuals who will so greatly benefit from the passage of Senate Bill 821, because of the essential ways that it will make routine opt-out HIV testing so much more accessible and accepted.

The 18 months leading to my diagnosis in July of 2006 were an odyssey of visits to doctor's offices and medical diagnoses. First it was ulcerative colitis, visits to a series of internists and gastroenterologists, and a subsequent colonoscopy. Then, in the summer of 2005, it was an emergency appendectomy and overnight hospital stay at a large Boston teaching hospital. And then it was more visits in 2006 to internal medicine physicians and dermatologists for chronic fatigue-related issues and skin conditions.

Not once — not a single time — in any of those numerous office or hospital visits over a year and a half, did any physician, nurse, or physician assistant ask for my consent to an HIV test. The first time I even had any indication that I might be HIV positive was two days before my

actual diagnosis, when an astute internal medicine doctor with years of HIV clinical experience pretty much diagnosed my condition without having to draw blood. It was that obvious to him.

By the time I started antiretroviral therapy three months later, as part of an NIH-funded drug study, my extremely low t-cell count (50, constituting an AIDS diagnosis) and my extraordinarily high viral load (2,000,000+ copies) indicated a case of HIV that, most likely, had had quite some time to replicate and replicate and replicate. The virus reached such a high level in my system, in part, because there is no routine testing for HIV in Massachusetts, and no one ever asked for my consent to an HIV test.

Not unlike my own complacency that led to HIV seroconversion, the medical field seemingly has become complacent itself about consistently testing the general public in a simple and streamlined fashion. I am, for better or worse, living proof that the HIV virus is alive and well and transmitting itself unnecessarily each day. Passage of Senate Bill 821 will help end the terrible consequences of such complacency, by making testing routine, commonplace, accessible and streamlined.

Today, thanks to the care of Dr. Paul Sax's Infectious Diseases group at Brigham and Women's Hospital, I am actually the healthiest I have ever been in my life. My t-cells are in the 500+ range, the virus is undetectable in my system, and I have intentionally lost more than 40 pounds in the last 16 months through a combination of smart eating and exercise. But I will probably never know what damage the virus did to my overall immune system. If someone had been able to conduct a routine HIV test five years ago, while giving me the option to opt-out, I certainly would have agreed. And quite possibly, I would have avoided not only other medical complications down the road, but also the possibility of transmitting HIV to others.

My very public statement in favor of this bill's passage was not without personal risk or backlash. I knew some of my friends and family would feel betrayed that I chose to disclose my status to them in this manner, and not in a more personal, one-on-one way. I apologize to them for that, and hope they are able to understand that my need to reveal my HIV status in the most public of ways – on the public record, at a legislative hearing, and in writing to you now – is very much to help others avoid what I endured. The way I look at it, only good can come from my testimony as presented to you. And only good can come from the passage of Senate Bill 821.

When Senate Bill 821 is passed, thousands of cases of HIV in Massachusetts will be diagnosed earlier, because routine opt-out testing is so much easier for patients and for the healthcare system. All of this will be a good step in the right direction of breaking away forever the stigma surrounding HIV. Thanks to advances in medications, research, and science, HIV is no longer the death sentence that it was twenty years ago. While I do not diminish the virus' insidious nature, HIV has also become a much more manageable condition, in that way not unlike diabetes. Patients can live long and deeply satisfying lives, while controlling their illness through medication therapies that carry few — if any — side effects. Last time I checked, diabetics do not wear a scarlet letter on their person.

Allow me to thank the Committee in advance for granting favorable and swift passage of Senate

Bill 821, and moving it forward for a vote on the House and Senate floors. The time for its passage most clearly has come.

Respectfully submitted,

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