

The New York City Council Committee on Health
HIV/AIDS-Hepatitis Co-Infection: Education, Prevention and Treatment
Testimony

My name is Ronni Marks. I am here today as a Hepatitis C patient and the facilitator of a Hepatitis C Patient Support Group. I'm also a Baby Boomer. The Institute of Medicine, the CDC, and other groups have recognized that Baby Boomers represent about two thirds of current Hepatitis C patients. As my generation grows older, the serious health effects of long-term Hepatitis C infection, including cirrhosis, liver failure, and liver cancer, will become a major burden on society. Improved diagnosis, treatment, and support services have the very real potential to reduce the dramatic increases in health care costs, as well as human misery, this trend is projected to cause. I appreciate the opportunity to talk with you about this emerging health crisis for people of my generation and many others.

I was diagnosed with Hepatitis C in 1997. I contracted the virus from a blood transfusion. But it doesn't matter how any of us contracted the virus, it just matters that we have a serious illness. At the time I was diagnosed, the Hepatitis C virus was newly identified and patients were virtually on their own to cope with the diagnosis and learn about their illness. There was no Internet information, no patient support groups, no advocacy organizations. I had successful careers in fashion design and executive recruiting, but after failing to respond to treatment I decided to dedicate myself to ensuring that Hepatitis C patients would not face the isolation and lack of information and support that I faced in 1997.

Since 2000, I have coordinated and facilitated the Mid-Town Manhattan Hepatitis C Support Group. The group meets at the NYU Langone Medical Center. I'm pleased that our group has become one of the largest and most successful support groups in New York City. But more groups like this one are needed

throughout the five Boroughs. As a support group facilitator and a Hepatitis C patient, I know the sense of isolation the disease can cause and the stigma we can feel. Despite being four times more prevalent than HIV/AIDS, public awareness of Hepatitis C is very, very low. The fact that Hepatitis C often does not cause symptoms for many years...until the disease has caused severe damage to the liver...may account for this lack of awareness and attention. Even many primary care physicians and other health care practitioners know little about Hepatitis C. This lack of public awareness and understanding fuels patients' sense of isolation and makes it more difficult...but also more important...for them to gain accurate information about Hepatitis C and its treatment. This year, the urgent need for improved access to information and help led me to form a non-profit organization, The Hepatitis C Mentor and Support Group, Inc., to foster the formation of patient support groups in New York and to provide patient mentoring services.

We are now on the verge of a major breakthrough in the successful treatment of Hepatitis C. In the past, only about 40 percent of Hepatitis C patients could get rid of the Hepatitis C virus through long and difficult treatment (many patients liken treatment for Hepatitis C to chemotherapy). But within the next few months, once new medications begin to become available, a much higher percentage of Hepatitis C patients will be able to eliminate the virus...to be cured. These patients will be able to lead healthy lives with a much lower risk of liver cancer or liver failure and the need for liver transplants. These cures will also reduce the spread of the virus. But the improved treatment will remain hard to tolerate and manage. In the near term, it will increase the need for medical and supportive services, including Hepatitis C patient support groups. Meeting this need will reduce long term health care costs, as well as the human toll of Hepatitis C.

Every week I receive calls from newly diagnosed Hepatitis C patients from every walk of life in New York City. They all feel the same need for accurate information about Hepatitis C and for support to manage the disease and its treatment with dignity and fellowship. Please help us increase public awareness of Hepatitis C and the promise of its successful treatment. Help us make sure that all New York City residents have access to Hepatitis C testing, treatment, and care.

Thank you.