

THE MENDED HEARTS, INC.

Statement
Presented by

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on

FISCAL YEAR 2007 APPROPRIATIONS

Before The

APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-EDUCATION
U.S. HOUSE OF REPRESENTATIVES

The Honorable Ralph Regula
Chairman

March 30, 2006
2:00 p.m.

Summary of Recommendations

National Institutes of Health: \$29.8 billion
National Heart, Lung, and Blood Institute: \$3.1 billion
National Institute of Neurological Diseases and Stroke: \$1.6 billion

The Mended Hearts, Inc. (MHI) is a national nonprofit organization that offers the gift of hope to heart patients, their families and caregivers for more than 50 years. Mended Hearts has 21,000 members operating through 280 community-based chapters across the country, with two in Canada. Chapters partner with more than 450 hospitals and cardiac care facilities in providing patient-to-patient support services. I have been appointed by the group as their legal representative—avolunteer position. And, I am a heart disease survivor.

About 30 years ago, I was diagnosed with a rare heart disease. After having chest discomfort and trouble breathing for more than two years, I was diagnosed with hypertrophic cardiomyopathy (HCM), a disease in which the heart enlarges. The heart muscle gradually thickens so much that heart cannot pump blood out effectively. The new heart muscle replacing the old heart tissue does not grow in the normal parallel pattern. Instead, it grows in a helter-skelter pattern. Studies show that 36 percent of young athletes who die suddenly have probable or definite hypertrophic cardiomyopathy, but it also affects men and women of all ages. HCM is one of the major causes of sudden death due to cardiac arrhythmias. There is no cure for HCM. However, medication may work, and there is surgery, which may alleviate the pain and discomfort, prolonging the patient's life. If surgery does not work, the alternative is a heart transplant, but donor organs are scarce. The doctor who made my diagnosis was trained at the National Institutes of Health's (NIH) National Heart, Lung, and Blood Institute (NHLBI).

Initially, I received several medications, which enabled me to engage in most activities. However, some activities, such as walking up hills, caused shortness of breath and severe chest pains. But, generally I could function normally. After about 10 years, the discomfort was increasing, and it became apparent that I was in serious trouble. I could not walk sixty feet without having to stop to catch my breath. Sometimes the pain was so severe that I would almost double over in the middle of the street. My wife told me later that my face would become gray. And the perspiration would pour off my body. The quality of my life had deteriorated so drastically that I knew I needed some treatment.

In 1988, I went to Georgetown Hospital for an angiogram—the gold standard for diagnosing heart problems. After the test, the cardiologist told me that he had bad news and worse news. The bad news was that I had a 95 percent blockage in my left anterior descending heart artery at the location known as the “widow-makers spot.” The worse news was that I had a major chance of suffering a severe heart attack, with less than a 5 percent chance of survival because of the HCM. At this point, my wife was quietly crying and I was perspiring profusely.

Because Georgetown Hospital did not have the expertise to operate on my condition, they called the NIH to see if they would accept me as a patient. I was sent home pending notice from NIH. I knew that I had run out of alternatives. No matter what the results, I needed treatment and I needed it immediately.

Subsequently, the NIH accepted me. After entering the NHLBI on February 9, my surgery occurred on February 11, 1998. No matter how trite the expression, it is very true—the day after surgery was the first day of the rest of my life. The surgery, a left ventricular myotomy and myectomy, was considered drastic. I was later told that the mortality rate was as high as 10 percent. That surgery is still done in only a few hospitals. It is considered the gold standard

for the treatment of HCM. This Murrow Procedure, in honor of the innovator, was developed and improved at the NIH.

Currently, there is a new experimental protocol in which the same effect is now being attempted by using alcohol to deaden the excessive heart tissue, instead of removing a piece of heart muscle from the heart's main pumping chamber, as was done in my case.

Now, I am on medication for the rest of my life. My condition is progressive. More than 10 years ago, I was fitted with a pacemaker to ensure that my heart beats at the correct rate. I am 100 percent dependent upon my pacemaker. Without the pacemaker, there are times when my normal heart beat is so slow that I could die.

I am eternally grateful to the physicians funded by the NHLBI, particularly to Dr. Charles MacIntosh and his staff, for the gift of life. Because of this marvelous doctor and research, I have lived eighteen years free of pain. I have seen two children graduate from college, witnessed the birth of three grandchildren, and shared these years with a wonderful wife. And, I have been able to work at my profession—attorney at law.

I have had the gift of life restored to me. To express my gratitude for that gift, under the aegis of the Mended Hearts, Inc., I visit patients recovering from heart episodes at two hospitals: Washington Hospital Center and Washington Adventist Hospital. Last year MHI visited more than 228,000 patients and their families in our mission of support. We have also made 6,700 visits over the telephone to give succor to these patients.

If this tale of woe is not enough, about 3 ½ years ago, I suddenly began to have mini-strokes. I experienced five episodes within 13 months. The last episode was just a year ago. Medication, including coumadin, now seems to have the incidents under control. Coumadin is a blood thinning drug that requires constant monitoring. At least once a month, I have to go to the hospital to get blood drawn from my arm to check the level of the drug.

To advance the fight against heart disease and stroke, I respectfully ask for the FY 2007 appropriations in the following amounts:

- National Institutes of Health: \$29.8 billion
- National Heart, Lung, and Blood Institute: \$3.1 billion
- National Institute of Neurological Disorders and Stroke \$1.6 billion.

My experience and my continued life is proof that the research supported by the NIH benefits not just the patients at the Clinical Center, but throughout the United States. The benefits go worldwide too.

Cardiovascular diseases remain the major killer of men and women in the United States. Nearly 40 percent of people who die in the United States, die from cardiovascular diseases. From 1979 through 2003, cardiovascular operations and procedures increased 470 percent.

Robert H. Gelenter, J.D.

Legal Representative, The Mended Hearts, Inc.

Robert H. Gelenter, J.D., of Rockville, Maryland is the legal representative of the Mended Hearts, Inc. MHI is a nonprofit organization offering the gift of hope to heart patients, their families and caregivers for more than 50 years.

Born and raised in the borough of the Bronx, in New York City, Mr. Gelenter received a Bachelor of Arts degree in 1953 from New York University.

He was employed as a documentary and newsreel cameraman for NBC News from 1961 until 1981. He has screen credits for 12 documentary films and has been on the team receiving an Honorable Mention from the Robert F. Kennedy Foundation, a first prize in the 1961 Biannual Venice Film Festival, 6 awards from the White House Photographers Association and two Emmys.

When the National Broadcasting Company abandoned film, he enrolled at the Columbus School of Law at Catholic University in 1970. He received his J.D. in October of 1975.

Gelenter started his legal career as the staff attorney for the Washington Area Law Center, a low profit law firm sponsored by the Central Labor Council of Washington, D.C. In 1983 he opened his private practice and is still practicing to the present time.

After his open heart surgery in 1988, Gelenter joined MHI. He has served his local D.C. Chapter as Vice President, President and Visiting Committee Chairperson. He is currently serving as the local chapter president.

Mr. Gelenter is also active on the national level of MHI, serving as Public Relations Committee Chair and now as legal representative for the organization.

In 1994 his local chapter named him Mended Heart of the Year. Gelenter was also honored as the National Mended Heart of the Year in 2001.

He also visits patients at The Washington Hospital Center and at The Washington Adventist Hospital.

Neither Mended Hearts, Inc nor Robert H. Gelenter receives Federal funds or grants.
