

STATEMENT

BY

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BEFORE THE

SUBCOMMITTEE ON EMPLOYMENT OPPORTUNITY

OF

COMMITTEE ON EDUCATION AND LABOR
UNITED STATES HOUSE OF REPRESENTATIVES

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Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco. I am National Liaison Chairman of the Metropolitan Washington Candlelighters. This association serves as the legislative arm of an international volunteer coalition of 225 groups of parents whose children have or have had cancer in 50 States, Canada and on every continent.

Children's cancer treatment successes have led the good news in cancer treatment for this decade. When my daughter was diagnosed in 1968, the possible cure rate for her cancer was less than 10%. Today the cure rate for acute lymphoblastic leukemia is 50% nationwide and 80% at centers of excellence in treating pediatric cancers.

NO CURED KIDS NEED APPLY

It is a tribute to the medical care teams treating our children that so many of our cured children aspire to medical professions. Those aspirations are not easy to attain.

For example, T.H., a cured Hodgkins patient with a residual pain problem, as a high school senior, met with state vocational rehabilitation representatives. It is her perception that this counselor tried to steer her away from a nursing career due to his misconceptions about cured cancer kids. He talked about her need to avoid infection, he cited anticipated employer resistance.

One would think that there would be no employer resistance in a hospital. After all they know the facts about the abilities of our kids and their cured status. They should take a certain pride in the advances in their medical profession that have made the cure of so many of our children possible.

Cured Candlelighter teens and young adults, male and female, have become pediatric nurses, surveyors in rehabilitation hospitals, medical social workers, recreation therapists with pediatric cancer patients, speech pathologists, etc.

However, the road to these jobs was not always easy. Some of

was 10 -- to be a navy pilot. He took his written naval aviation reserve officers candidate exams and passed them and his flight physical with flying colors. During his physical the naval doctor asked what his scar was from, 30 minutes later he said because of the history of Hodgkins he could not be accepted in the program; he could not even enlist in a an emergency to serve his country. They do not want him. He feels as if they consider him a used car.

D.N. was diagnosed with a malignant tumor in 1975. She has had no treatment since it was surgically excised. She is a party to a lawsuit that alleges that she was refused a police department job because she has had cancer.

Her concern is the children with cancer. What if "one of my children was diagnosed with cancer at 3? Twenty years later -- could they get a job -- probably not".

D.F. was diagnosed with acute lymphatic leukemia in January of '78 at age 16 years 9 months, he has been off all treatment for almost 5 years. He has tried to enlist in all branches of the armed services -- navy, air force, army, coast guard and marines. The marine officer who turned him down told him it was one of the hardest things he had to do since at 6'3", 190 lbs., perfect health and perfect physique he looked like a marine. He has passed all his tests and physicals; he is considered cured by his doctors.

What of our cured kids who have been left with minor neurological deficits. R.K. had a brain tumor. The student is pursuing a masters in social work and has finished all but one subject which is necessary before she can begin her internship. She has flunked the test twice in the law unit subset.

The reason she flunked is not because she fails to have the substantiative knowledge but because of the brain tumor she cannot function at the speed necessary to take the test in the normal manner. The school offered her the opportunity to take the course again in the fall. However this would have delayed her entry into the requisite internship program which is part of the MSW degree program. The lack of an alternative testing system for her is attributed to a particular professor's attitude but that attitude has been adopted by the school of social work. It may take a lawsuit to insure that our children who have the complete understanding and complete ability to do the work but need a little more time because of the effects of their chemotherapy and radiotherapy can get what their competence deserves.

The problem is very real. It certainly is confirmed by the smattering of examples that I have given you above. It is also confirmed by a study entitled "Psychological Consequences of Childhood Cancer Survival" which was presented at the annual meeting of the Society for Epidemiologic Research in Houston, TX

The response rate of 84% yielded a sample size of 1037 study subjects consisting of 450 survivors of childhood cancer and 587 of their siblings. The appropriate matching procedures yielded very similar sex and age frequency distributions.

There was substantial evidence from these data that male survivors experienced significantly more rejection from the armed forces, college and employment than do their siblings. Of those who applied, 80% of male survivors were rejected from the military versus 18% male siblings; for college admissions the percentages were 13% and 3% respectively. The differences with respect to employment were also significant, but not as disparate 32% versus 21%. In contrast to the male differential, equal percentages of females survivors and siblings, 19% were denied employment. Females survivors were also significantly more likely to be denied entrance into the military. There appeared to be less rejections from graduate school among survivors of both sexes than among controls, although the differential was not significant.

Both male and female survivors were denied life insurance and health insurance more frequently than their siblings. Of those who applied, 24% of male survivors and 19% of females survivors were denied life insurance, 14% male and 9% of females were denied health insurance, in contrast to a negligible number of controls denied insurance of either type.

Congressman Biaggi has introduced Bill #H.R. 5849, called the Cancer Patient's Employment Rights Act. In the preamble to that Bill, Congressman Biaggi cites that approximately 25% of all individuals with a cancer history are victims of cancer related employment discrimination, including job denial, wage reduction, exclusion from and reduction in benefits, dismissal and promotional denial.

The purpose of his Act is to discourage employment discrimination against an individual based on cancer history; to encourage employers to make reasonable accommodations which assist the employment of an individual with cancer history; to increase public recognition of the employability of individuals having a cancer history; and to encourage further legislation designed to prohibit discrimination against individuals with cancer history in areas other than employment discrimination.

The most important part of the Act from the point of view of our children is the following:

It shall be unlawful employment practice for an employer, employment agency, or labor organization to require as a condition of employment an employee or perspective employee with a cancer history to meet medical standards which are unrelated to job requirements, or to require such employee or perspective employee to submit to a physical exam

them with statistical evidence that at a certain point in time our children should be considered a normal risk in terms of employment and insurance characteristics. Can you help us compile this data? Search your files for statistics on each major subgroup of cancer in our children to show how treatment has changed and how the longevity of our children have improved. We need to provide a base line against which the insurance companies and employers can measure the wellness and risks posed by our children break down the barriers to employability and insurability.

Second, we need guardian angels of a special kind. Even armed with the best statistics, the weight and voice of one cured child, seeking first time employment is not likely to prevail against the barriers. You can help. How? Each major cancer center should have an office, program or position of ombudsman or advocate on issues of discrimination in employment and education. These persons would accompany the cured patient to make the point of cure emphatically to the putative employer or educational institution -- private, government or state.

What this presence and involvement will say to the potential discriminators is that we are not just giving lip service to discrimination, we are putting our power, resources and reputation out front to do battle for our qualified, competent cured cancer children's rights.

Mr. Chairman, Members of the Committee, on behalf of parents of children with cancer throughout the world, I should like to commend you for your efforts and for your understanding of our problems.

We gratefully acknowledge the opportunity to submit this statement.