

**GENETIC TESTING FOR CYSTIC FIBROSIS:
A PERSONAL PERSPECTIVE**

*Suzanne P. Tomlinson**

I believe in the value of information and in the individual's right to know as much as possible about herself and her future. However, the decision by a panel of experts convened by the National Institutes of Health ("NIH") that all pregnant couples or couples planning a pregnancy should be offered genetic testing to detect the presence of the gene that causes cystic fibrosis ("CF") has caused me to reevaluate this central tenet.¹ In my opinion, this panel's decision to recommend that people obtain genetic tests and use them to essentially reduce the number of children who are born with CF is inappropriate. It is one thing for individuals to determine how to use this information for their own lives, but quite another thing for society to dictate how this information should be used. I fear the inappropriate use of prenatal testing for CF will unnecessarily reduce the number of people with CF and undermine incentives for the development of a cure for this disease.

I challenge the appropriateness of the recommendation that prenatal testing for CF be offered to all pregnant couples, especially in the absence of reliable mechanisms to ensure truly informed decisions. We, as a society, should focus on developing new treatments for CF and other genetic conditions, rather than encouraging the use of prenatal genetic tests to eliminate the disease. Given the premium society places on "perfection" and the absence of adequate social acceptance and support for people who are less than perfect, prenatal CF testing may actually reduce parental choice by subtly conveying that it is unacceptable for someone to bear a child with an imperfection that could have been prevented, albeit by preventing the birth itself.

* Ms. Tomlinson is a lawyer for the Biotechnology Industry Organization ("BIO"), where she addresses issues such as genetic nondiscrimination, medical privacy, and cloning. This commentary is based on her presentation at the first meeting of the American Medical Association on genetic testing, which was held in New Orleans, Louisiana, in March 1998.

For more information on cystic fibrosis, contact the Cystic Fibrosis Foundation, 6931 Arlington Road, Bethesda, MD 20814; 1-800-FIGHT-CF.

1. See *Genetic Testing for Cystic Fibrosis*, NIH CONSENSUS STATEMENT, Apr. 14-16, 1997, at 24.

MY LIFE WITH CF

I was diagnosed with cystic fibrosis in 1964, at seven months of age. At the time, there were few treatments for CF and little hope for people with the disease. My parents, referring to the current literature about CF, realized that I had a fifty percent chance to live to graduate from kindergarten. But I have now graduated from law school. By the time I was old enough to understand the statistics about my life, I had outgrown them.

I have been very fortunate to experience few serious complications as a result of this disease. I take pancreatic enzyme supplements with every meal to aid in digestion and antibiotics to fight occasional colds and lung infections. I perform chest physical therapy every morning, using aerosols and Pulmozyme to loosen the mucus that clogs the airways. This enables me to cough up the mucus and reduces the chance of lung infections.

I have maintained this regime since childhood, with hospitalizations for an intestinal blockage, appendicitis, and sinus surgeries. I have had few lung infections, with no episodes requiring hospitalization. However, I recently developed diabetes as a side effect of CF and am taking insulin daily. I also have participated in numerous clinical trials, including the Pulmozyme trial.

I have many friends with CF, several of whom are older than I and who are doing quite well. Some are younger and have struggled more with their health, even to the point of requiring lung transplants. All appreciate their struggles and their good health. All of us are anticipating new drugs to treat and cure the lung infections, which could give us a "new lease on life."

INFORMATION ABOUT CF

I believe CF is a manageable, chronic illness. It is a genetic disease that can affect an individual's respiratory, digestive and reproductive systems. An individual must inherit two copies of the gene, one from each parent, to be born with CF.² It primarily affects Caucasians, specifically individuals of northern European descent, a population in which the gene is relatively common. However, the disease is still a rare

2. See *id.* at 5 (referring to CF as an autosomal recessive disease, which is a genetic disease that must be inherited from two carriers, each having one gene).

genetic disease, with only 23,000 people with CF living in the United States.³

Approximately 35.6 percent of the CF population are now adults.⁴ It is estimated that half the population will be adults by the year 2000.⁵ "A survey in 1995 reported that 35 percent of young adults with CF worked full-time, and almost 90 percent had completed a high school education."⁶

People with CF can and are living productive lives, attending high school and college, getting married and having careers. The current life expectancy is about thirty-one years of age.⁷ However, for individuals born today with CF, the life expectancy may be much higher.⁸

OBTAINING GENETIC TESTING

My avid interest in participating in CF research led me to have my genotype determined. A research lab asked to test my blood and offered to test my husband's as well. They tested for the most common mutations based on our family heritage. It is impossible to test for all mutations, for over 700 have been identified.⁹

We learned that I carry two copies of the main mutation for CF, delta F508, which is found in over seventy percent of people with CF. There are varied levels of health with CF, which can be somewhat attributed to the genetic mutations. More research is needed to determine the correlations between genotype and phenotype. Even among people who are homozygous — have two identical copies — for this mutation, health status varies.

3. See Memorandum from Stacy C. FitzSimmons, Cystic Fibrosis Foundation, to Cystic Fibrosis Care Center Directors, Patient Registry Coordinators, and Cystic Fibrosis Colleagues (Sept. 8, 1997) (on file with the *Harvard Journal of Law & Technology*) [hereinafter FitzSimmons Memorandum].

4. See FitzSimmons Memorandum, *supra* note 3, at 1.

5. See Barbara L. Palys, *Genetic Screening for Cystic Fibrosis: Establishing a New Precedent?*, IACFA NEWSL., July 1997, at 20, 23.

6. See FitzSimmons Memorandum, *supra* note 1, at 5.

7. See FitzSimmons Memorandum, *supra* note 3, at 1, 19.

8. See Neil A. Holtzman, *A Standard of Care for Cystic Fibrosis Carrier Screening: Satisfying Equity and Autonomy*, in NIH CONSENSUS DEVELOPMENT CONFERENCE, GENETIC TESTING FOR CYSTIC FIBROSIS: PROGRAM AND ABSTRACTS 99, 101 (1997).

9. E-mail message from Carolyn Habberset, Cystic Fibrosis Foundation, to author (Dec. 5, 1997) (on file with author) (forwarding message from Lap-Chee Tsui, Geneticist-in-Chief, Department of Genetics, The Hospital for Sick Children, Toronto).

We learned that my husband does not carry any of the common mutations for CF. Thus, it is unlikely that we could have a child with CF. Rather, we fear the impact of pregnancy on my health, particularly since I developed diabetes last year. However, we would welcome a child with CF.

COUNSELING

Genetic counseling is essential to appropriate use of genetic tests. My husband and I did not receive any counseling with our testing, however. In fact, I told my husband the news. I have been active in the CF community since childhood, participated in research since high school, and previously worked at the Cystic Fibrosis Foundation for eight years. I assume these researchers knew my proactive nature and believed that I — and my husband — did not need counseling. Yet, I hold firmly that nondirective genetic counseling is essential to appropriate, informed use of genetic tests.

FUTURE RESEARCH

One of the primary reasons for the increased life expectancy of people with CF is the improvement in our medical armament against disease, including the development of antibiotics. In my lifetime, the industry has developed one drug to treat the symptoms of CF; Pulmozyme thins the mucus in the lungs, allowing it to be coughed up more easily, thus reducing the chance of lung infections.¹⁰ The drug has been available since 1993, and it has reduced the need for hospitalizations, thereby improving the quality of the lives of people with CF. In December, the Food and Drug Administration ("FDA") approved the first inhaled antibiotic to treat CF, TOBI, an inhaled form of tobramycin.¹¹ Clinical trials showed that it increased the lung function of people with CF up to eleven percent during six months of treatment.¹²

The future looks even brighter, with a plethora of new treatments on the horizon that are being pursued by biotechnology and pharmaceutical

10. See Preston W. Campbell, III, *Cystic Fibrosis Therapy*, in NIH CONSENSUS DEVELOPMENT CONFERENCE, *supra* note 8, at 23, 23. (Pulmozyme is referred to as rh DNase I. For more information on Pulmozyme, contact Genentech at 460 Point San Bruno Blvd., South San Francisco, CA 94080-4990).

11. See *Antibiotic Inhalant Approved for Treating Cystic Fibrosis*, WASH. POST, Dec. 24, 1997, at A4.

12. See *id.*

companies,¹³ guided and prodded by the Cystic Fibrosis Foundation. Researchers are targeting the genetic cause of the disease.¹⁴ Scientists are identifying virus vectors that can shuttle healthy copies of the CF gene into the airways to alter the cells lining the airways. I am hoping to be one of the many thousands of people with CF to benefit from the new treatments underway.

Genetic research leads to the development of genetic tests to detect disease long before it leads to genetic treatments for such diseases. A test to detect the genes that cause CF has been available nearly since the discovery of the gene in 1989. Now, scientists have discovered over 700 different versions of the gene that causes CF with varying degrees of severity.¹⁵ Again, how the genetic mutations relate to severity of disease is not known for most mutations. Since I am homozygous for the main mutation that causes CF, I might not have been born if prenatal testing were available thirty-five years ago.

Despite these advances in understanding and treating the disease and the increasingly optimistic outlook for people with CF, genetic testing for CF is becoming more widely recommended.

NIH CONSENSUS DEVELOPMENT CONFERENCE

In April 1997, the NIH convened a panel of experts in medicine and law along with members of the public to assess the scientific evidence regarding genetic testing for cystic fibrosis. The panel did not include physicians or health professionals caring for people with CF; however, they presented the latest research and approaches to care to the panelists. Individuals with CF could not be on the panel, and did not formally present comments; however, several individuals, including myself, made statements about positive trends in CF research and our quality of life during an informal public comment session.

The Panel's Recommendations

The panel concluded that:

- Active research should continue on improved treatments for people with CF, enhanced

13. See Campbell, *supra* note 10, at 23-25.

14. See *id.* at 24.

15. See *supra* note 9 and accompanying text.

molecular diagnosis of CF, and better understanding of the pathophysiology of CF.

- Over the past two decades, aggressive management of the pulmonary manifestations of CF and new treatment modalities have resulted in much longer survival.
- More than 90 percent of CF mutations can be identified in certain populations. Although generally good correlations exist between certain CF mutations and pancreatic status, it is known that CF mutations are not robust predictors of severity of disease and longevity.
- The goal of genetic testing is to provide individuals with information that will permit them to make informed decisions.
- *CF genetic testing should be offered to adults with a positive family history of CF, to partners of people with CF, to couples currently planning a pregnancy, and to couples seeking prenatal care.*
- Comprehensive educational programs are recommended, utilizing a variety of media, for health care professionals and the public.
- Counseling services must be accurate and provide balanced information to afford individuals the opportunity to make autonomous decisions. Every attempt should be made to protect individual rights and genetic and medical privacy rights and to prevent discrimination and stigmatization.
- Access to genetic testing in the prenatal setting enhances the ability of couples to make reproductive choices, as shown by their interest in and use of the information they gain. The cost is reasonable in relation to the benefits obtained.
- Offering CF genetic testing to the general population or to newborn infants is not recommended.
- Genetic testing for many additional conditions will be available in the future. Some of the principles considered for CF genetic testing might well have broader application.
- It is essential that the offering of CF carrier testing be phased in over a period of time in order to ensure that adequate education and appropriate

genetic testing and counseling services are available to all persons being tested.¹⁶

Evaluating the "Goals" of Testing

The panel decided that, while CF genetic testing should not be offered to the general population, it should be "offered to . . . couples currently planning a pregnancy, and to couples seeking prenatal care."¹⁷ Despite this careful wording, the panel's recommendation was interpreted more broadly. According to *The Washington Post*, "[i]t was the first time a panel such as this has backed *population-wide* testing for a genetic disease. Other genetic tests are recommended for people known to be at high risk for a specific inherited disease such as Tay-Sachs."¹⁸ Therefore, the panel essentially recommended a significant expansion of prenatal testing services.

The panel in effect expanded the offering of testing to all individuals who would use this information — all couples planning a pregnancy. The panel felt the information about genetic status was only relevant in a context of potential childbirth. They noted that individuals would want to use this information to make decisions regarding childbirth, not that the information is valid by itself. The panel recommended that the test should be actively "offered" rather than passively "made available" to couples. This implies that the medical community *endorses* the use of this test and the actions that couples should take if the test is positive.

The panel determined that testing for the general population is not appropriate because of the "low incidence and prevalence of CF and the demonstrable lack of interest in the general population."¹⁹ On the other hand, they noted that there is "a significant level of interest in CF testing" in couples planning a pregnancy.²⁰ The population planning a pregnancy could use this information to: (1) be reassured that their pregnancy is not affected; (2) prepare for the birth of a child with CF; or (3) terminate an affected pregnancy. Over ninety-nine percent of couples receive reassuring information about the likelihood of bearing a child with CF.²¹

16. *Genetic Testing for Cystic Fibrosis*, *supra* note 1, at 24–25 (emphasis added).

17. *Id.* at 24.

18. *Cystic Fibrosis Testing for Potential Parents*, WASH. POST, Apr. 17, 1997, at A24 (emphasis added).

19. *Genetic Testing for Cystic Fibrosis*, *supra* note 1, at 16.

20. *Id.*

21. *See id.* at 13.

The panel noted that "[t]he goal of genetic testing is to provide individuals with information that will permit them to make informed decisions."²² However, the true goal of reducing the number of affected births was never stated. "It is popular to articulate the goal as improved reproductive decisionmaking, and not as a reduction in births of affected individuals."²³

Newborn Screening

If the true goal of prenatal testing were to encourage informed decisionmaking, the panel also would have recommended genetic testing for all newborns. Newborn screening was not recommended because two-thirds of individuals with CF are already diagnosed by the first year of age, and begin to receive appropriate care. The panel stated "[s]tudies have not provided sufficient evidence that identifying CF patients earlier than the current average age of diagnosis improves outcomes."²⁴ Thus, it would be difficult for the panel to propose that prenatal testing could be used to help people prepare during pregnancy for the birth of an affected child, if they do not also recommend testing of newborns to improve health outcomes.

Cost-Effectiveness of Testing

The panelists said they were not encouraging selective termination of affected pregnancies, nor were they sending a negative message to people with CF.²⁵ However, the discussion of the cost-effectiveness of testing based on the number of affected fetuses identified and terminated undermines these arguments. According to the panel's report, "the cost per identified CF fetus averted ranged from \$250,000 to \$1,250,000 for a Caucasian population of Northern European ancestry," the most relevant population due to the sensitivity of the test and the prevalence of the disease in this population.²⁶ The panel noted that the test would reassure ninety-nine percent of population that their child would not be born with CF.²⁷ However, even if a cure for CF is developed in the near

22. *Id.* at 24.

23. See Benjamin S. Wilfond, *Normative Issues in Developing Public Policy for Cystic Fibrosis Carrier Testing*, in NIF CONSENSUS DEVELOPMENT CONFERENCE, *supra* note 8, at 103, 104.

24. *Genetic Testing for Cystic Fibrosis*, *supra* note 1, at 17.

25. *Cystic Fibrosis Testing for Potential Parents*, *supra* note 18, at 24.

26. *Genetic Testing for Cystic Fibrosis*, *supra* note 1, at 15.

27. See *id.* at 13.

future, the cost of caring for people with the disease would likely increase. Thus, the cost-effectiveness of prenatal testing for CF would also improve, further justifying its use.

Potential Liability Concerns

As a lawyer, I suspect that the physicians' fear of medical liability following the birth of a child with CF to a couple who did not access this test plays a significant role in expanding the use of the test. The decision by the American College of Obstetricians and Gynecologists ("ACOG") to recommend the wide use of prenatal tests for maternal serum alpha fetoprotein ("MSAFP") screening in 1985 recognized the potential legal liability as a concern.²⁸

The Variable Nature of the Disease

While a genetic test for CF can indicate that someone carries one or two copies of the CF gene, it cannot determine if the individual's health will be severely impacted by the disease. Although scientists have identified over 700 mutations of the CF gene, they have only shown a correlation between some genes and the severity of the disease's impact on the digestive problems and on some reproductive deficiencies. For instance, some men who carry mutations of the CF gene appear to be healthy with the exception of one feature of CF — congenital bilateral absence of the vas deferens ("CBAVD")²⁹ — which causes infertility. Some women with a similar genotype are normal or have mild sinus problems.³⁰ With limited knowledge of the mutations involved, some desired pregnancies may be terminated based upon inaccurate predictions of future clinical symptoms.³¹

Most importantly, scientists have not identified a correlation between genetic mutations and the prevalence and severity of lung disease, which is the primary symptom that can cause the most life-threatening complications. The severity of the disease may be influenced by variations in other genes.³² Without a clear correlation between genotype and the severity of the disease, the widespread use of

28. See Wilfond, *supra* note 23, at 103.

29. See Garry R. Cutting, *Genetic Epidemiology and Genotype/Phenotype Correlations*, in NIH CONSENSUS DEVELOPMENT CONFERENCE, *supra* note 8, at 19, 21.

30. See *Genetic Testing for Cystic Fibrosis*, *supra* note 1, at 9.

31. See Palys, *supra* note 5, at 23.

32. See Cutting, *supra* note 29, at 21.

genetic testing for CF to determine whether to terminate otherwise wanted pregnancies is inappropriate.

The Applicability of the Test for All Populations

Another controversial aspect of the panel statement is the recommendation that testing be offered to all couples despite ethnicity or race. But CF is most common in Caucasians, occurring with an incidence of one in 3,300 live births.³³ The disease is less common among Hispanics, and much less common among African-Americans and Asian-Americans.³⁴ The clinical sensitivity of CF genetic tests for other racial and ethnic populations is also much less precise, leading to a greater chance for uninformative test results and improper conclusions that the pregnancy is or is not affected by CF.³⁵

Phasing in the Recommendations

The panel recognized that health professionals and the public must be educated about CF and the implications of genetic testing. The NIH convened another panel in October 1997 to identify ways to phase in the recommendations, and to educate relevant parties. As a member of this panel, I reminded the participants that CF is a variable disease, with an increasingly large population of adults and a plethora of treatments on the horizon. Recommendations are still being determined as to the best means by which to phase in the tests.

EDUCATING PEOPLE ABOUT CYSTIC FIBROSIS

To use prenatal tests for CF in the most responsible manner, health professionals and the public must have a thorough understanding of the disease and its variable effect on individuals. They must recognize and convey the fact that people are living longer, healthier lives with this disease.

To educate people best about CF, information about genetic testing for CF must be very precise and disease-specific. Testing options cannot be offered in a general format or in the context of many other diseases, some of which are much more severe. Each disease, with its genetic or non-genetic basis, is different. People must have specific knowledge

33. See *Genetic Testing for Cystic Fibrosis*, *supra* note 1, at 7.

34. See *id.* at 7-8.

35. See *id.* at 8-9.

about CF in order to make an informed decision about the relevance of the test to their lives and its usefulness for their decision about delivering and caring for a child with the disease.

The decision to *forego* genetic testing must remain just as much a voluntary option as the decision to *take* the test. Furthermore, it is also an individual decision to use the information from the test in a way that best suits each individual's life. My hope is that some individuals will decide to continue pregnancies despite the knowledge that the outcome will be children with CF. Once this decision is made, it must be fully supported by medical professionals, health insurers, and society.

TESTING FOR CF: THE BIG PICTURE

The prenatal test for CF is only one of many tests to predict the health of an unborn child. More tests are being developed to detect many genetic abnormalities in utero. At the same time, new treatments or cures are being pursued for genetic diseases.

As the capability to identify more genetic diseases prenatally becomes available, it will be increasingly difficult to distinguish between each disease and the current state of medical care and quality of life for individuals living with these diseases. It will be even more challenging for health professionals to convey these differences to young couples anticipating the birth of their child and for these new parents to make decisions that will affect their lives and determine the future (if any) for their child. Just because we know the genetic basis of a disease and *could* detect it in utero, it does not mean that we *should* do so if the only type of treatment is selective termination. In my opinion, until we have treatments and cures for genetic diseases, we should carefully examine the purpose for which these tests are advocated.

To ensure that this technology is used to expand parental choice rather than advance societal intolerance for imperfection, we should strive for open public discussion and consensus to establish safeguards to determine the most responsible use of these tests. We must carefully assess the development and usefulness of these tests to ensure that health professionals and society understand the tests and the diseases being identified, before we accept them as the standard of care and as a means to avoid legal liability.

We have made tremendous progress in overcoming many prejudices we hold against people who look different — both in racial and ethnic variations and in physical disabilities. We have passed laws to protect the most vulnerable members of our society by prohibiting discrimination in employment and facilitating access to public places,

most notably through the Americans with Disabilities Act.³⁶ We are sustaining the lives of people who suffer serious traumatic injuries and who are adjusting to lives in wheelchairs and on respirators.

However, we are now faced with the option of using a new technology to eliminate certain genetic diseases — and people with those diseases. We must continue to protect the most frail in our society. We should not give a message of demeaned value to people with disabilities and a message to potential parents of children with certain genetic traits that they are irresponsible for not using prenatal tests to terminate an affected baby. Rather, society — medical professionals, insurers and consumers — should support an individual who decides to have a child with CF or another genetic disease. Genetic medicine should be used to benefit society, determined by each of us, not as some global means of “improving” the human race.

We look to genetic testing as the crystal ball through which we can glimpse our medical futures and those of our children, both born and unborn. While genetic information can give us some idea about our future, the picture is not very precise. It cannot show us the many variables in the environment and the impact of other genetic or non-genetic factors on our future. By putting the promises and limits of genetic information in context, we can better gauge our expectations of predictability from this information. Like a weather forecaster predicting the force of a storm, genetic testing for most conditions cannot state with certainty how someone will be impacted;³⁷ one may take precautions — make lifestyle changes — to minimize exposure.

We would like to give our children the best chance for a long, healthy future, but at what cost to our society? Do we want to ensure that our children do not inherit a gene that could predispose them to breast cancer, or that they do carry a gene for intelligence, for instance? When we examine the desires of an individual who wants to select the entire genetic make-up of their child through “cloning,” we immediately reject this notion as egotistical and an attempt to play God.³⁸ We must recognize the potential negative social implications of today’s prenatal tests for diseases like CF as well.

36. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (1994).

37. See Eric T. Juengst, *The Ethics of Prediction: Genetic Risk and the Physician-Patient Relationship*, 1 GENOME SCI. & TECH. 21, 23 (1995).

38. See, e.g., Jennifer S. Bard, *When a Woman Doesn't Need a Man: Legal Issues Regarding Cloning as an Infertility Treatment*, J. BIOLAW & BUS., Spring 1998, at 56, 56 (listing “wealthy individuals reproducing themselves to overcome mortality” as a misuse of cloning technology).

CONCLUSION

With the advances in medicine in my lifetime, we are well on the road to developing a cure — or life-saving treatment — for CF. It seems inappropriate to recommend the widespread use of prenatal testing for CF at this time. By the time health professionals and the public are sufficiently educated about CF, half the population of people with CF will be adults — most living full, active lives. And we will be that much closer to a cure.

Biotechnology and pharmaceutical companies are struggling to use genetic information to identify new treatments and cures for CF and other diseases.³⁹ Every day, scientists identify a gene or a genetic link for more diseases, including cancer and Alzheimer's. They must carefully choose which diseases they will target for new treatments.

Part of this decision is based on the number of people living with the disease. CF is an "orphan disease," as it affects fewer than 200,000 people. The Orphan Drug Act of 1983⁴⁰ was passed in an effort to encourage companies to invest in treatments for people with orphan diseases. The Cystic Fibrosis Foundation is doing an admirable job of raising and investing in research to cure CF,⁴¹ and in finding new ways to stimulate drug development.

The CF Foundation recently announced an innovative "Therapeutic Development Grant Program," which provides matching funds to companies developing new therapies for CF.⁴² Despite these efforts to stimulate development of treatments for CF, fewer companies may decide to search for a cure for CF as the population of people with CF is reduced by virtue of prenatal genetic testing.

While we all passionately agree that we do not want to experience any disease either personally or through a family member, we must not lessen society's acceptance of people with disease. In addition to genetic

39. These companies include Biogen, Inc.; Genentech, Inc., which developed Pulmozyme to thin the mucus in the lungs; Genzyme Corp., which has developed genetic tests and is using genetic therapies to search for new treatments; GlaxoWellcome, plc; PathoGenesis Corp., which developed TOBI to treat CF-related lung infections; and Targeted Genetics Corp..

40. Pub. L. No. 97-414, 96 Stat. 2049 (codified as amended in scattered sections of 15 U.S.C., 21 U.S.C., 26 U.S.C., 35 U.S.C., & 42 U.S.C.).

41. See David Stires, *Sweet Charity*, SMARTMONEY, Dec. 1997, at 93, 98-99 (recommending the Foundation to potential donors based on its efficiency and favorable reviews from charity watchdogs).

42. See Cystic Fibrosis Foundation, *Building Bridges to a Cure* (program description on file with author).

testing capability that may be used for better diagnosis and care, biotechnology will make living with CF more achievable. It already has.

With the development of new technologies comes new responsibilities. We must ensure that our children and our children's children have access to the best new treatments that genetic research can bring. It would be a tragedy if some children were deemed unworthy of benefitting from these treatments. All children have a right to be born and to experience all that life can offer. We must strengthen our resolve to bring new treatments and cures to our children as quickly as possible. We also must strive to deliver them into a society that accepts all children regardless of race, ethnicity, or genetic disability.