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New York Legal Assistance Group

Testimony by LegalHealth a division of the New York Legal Assistance Group on Proposed Resolution No. 918-A - An act to amend the Social Services law, in relation to coverage for healthcare services under the basic health program for individuals whose immigration status renders him or her ineligible for federal financial participation

October 31, 2019

Chairpersons Rivera and Levine, Council Members and staff, good morning and thank you for the opportunity to share our support for Resolution 918-A. My name is Domna Antoniadis, and I am a Senior Staff Attorney in the LegalHealth Division of the New York Legal Assistance Group (NYLAG,) a nonprofit law office dedicated to providing free civil legal services to low income New Yorkers. NYLAG serves immigrants, seniors, veterans, the home bound, families facing foreclosure, renters facing eviction, low- income consumers, those in need of government assistance, children in need of special education, domestic violence victims, people with disabilities, patients with chronic illness or disease, low-wage workers, low income members of the LGBTQ community, Holocaust survivors, as well as others in need of free legal services.

LegalHealth is the nation's largest medical legal partnership, providing general legal assistance in the healthcare setting to patients of hospital and community health centers. We complement healthcare with legal care to address the non-medical needs of individuals with serious health conditions. LegalHealth has legal clinics at 36 health facilities and our staff has collectively worked with thousands of seriously ill immigrants. As an attorney with LegalHealth, I staff the legal clinic at the Bellevue Cancer Center. Over the past 5 years, I have witnessed firsthand how one's immigration status is a social determinant of health

NYC is home to over 3.1 million immigrants and over 500,000 are undocumented[1]. These individuals are integral members of our community and help make New York the diverse city we are so proud of. But these members of our community are denied a basic need, the ability to access comprehensive health insurance. Adult undocumented immigrants are barred from purchasing most insurance or qualifying for public insurance. In 2011, 71% of undocumented immigrants were uninsured; the remainder were primarily insured through employment.[2]

[1]State of Our Immigrant City, March 2018. Available at: https://www1.nyc.gov/assets/immigrants/downloads/pdf/moia_annual_report_2018_final.pdf

[2] As of 2015, 72% of the undocumented immigrant population was between age 18 to 44; just 17% of unauthorized immigrants were age 45 to 64. Only 1% of these immigrants were age 65 or older,

Leaving such a large population uninsured has profound implications on safety net hospitals and the local government and private sources that fund these institutions. This plays out in a lack of access to preventative care, mental health services and lifesaving treatments such as transplants or clinical trials. In the case of the latter, a premature death can mean economic instability for a family who relied on the decedent to support them and shifting the burden to the larger community. My testimony will focus on undocumented immigrant access to such lifesaving treatment.

Physicians at acute care facilities routinely refer undocumented immigrants to our legal clinics because in many situations, without insurance, the medical team cannot treat the patient following normal standards of care. In essence, healthcare providers must shift the burden of care to a legal service provider for solutions to the treatment dilemma. This is particularly problematic because the time necessary to appropriately address complex immigration and insurance legal issues is substantially longer than most patients have.

versus 13% of the total U.S. population. In: Capps R, Fix M, Van Hook J, et al. A Demographic, Socioeconomic, and Health Coverage Profile of Unauthorized Immigrants in the United States. Migration Policy Institute; May 2013.

These occurrences are not new or unique. In the past 5 years alone, I have worked with over 200 patients whose providers could not provide medically appropriate lifesaving or life improving treatment without my legal involvement. In this same time period, LegalHealth has worked with over 1,750 patients in a similar position. Let me describe several clients to illustrate this further.

One client, a 34-year-old named Luis, had lived in the United States for nearly 20 years and was the proud father of 4 young children. He was diagnosed with acute leukemia - an aggressive cancer but was an ideal candidate for a donor-based stem cell transplant and possible clinical trial enrollment. However, because he was uninsured and undocumented his treatment was irregular until he was finally referred to Bellevue, where I met him. We ultimately, successfully applied for a rare humanitarian request to the Department of Homeland Security called deferred action. It took many months of intense legal advocacy before Luis was able to be referred to a transplant hospital. But it was too late. He was quickly relapsing and died without ever getting the transplant. His wife, who never used food stamps or public assistance for their children, was forced to apply for every type of benefit available just so they could survive.

Cases like this have a profound impact on healthcare providers. A recent study published in the Annals of Internal Medicine found, "that providing

undocumented patients with suboptimal care because of their immigration status contributes to professional burnout and moral distress." [3] In this study, the researchers identified that many providers intentionally remain detached from patients or were so distressed that they transitioned to other health settings.

Indeed, many of the oncology fellows I work with have specifically referenced their experience with undocumented immigrant patients as one of the reasons why they are leaving the ppublic hospital system. As one fellow told me, "I love that at Bellevue I can truly practice medicine but what's the point if I can't even treat some of my patients." While Bellevue may be the largest safety net hospital in NYC, we have seen similar frustrations and feelings of helplessness across all medical disciplines in both public and private hospitals.

Ultimately, a transplant for Luis, and those like him, would have been far more cost effective than continuing with chemotherapy and end of life (EOL) care. Cost benefit studies comparing, for example, stem cell transplants versus

[3] Cervantes L, Richardson S, Raghavan R, et al. Clinicians' Perspectives on Providing Emergency-Only Hemodialysis to Undocumented Immigrants: A Qualitative Study. Ann Intern Med. 2018;169:78–86. [Epub ahead of print 22 May 2018]. doi: 10.7326/M18-0400

chemotherapy for certain cancers[4], or kidney transplants vs dialysis[5] consistently show major direct medical savings as well as adjusted life years.

While EOL care is costly, it is especially so for cancer patients. According to a study published in the Journal of Oncology Practice, in the last six months before death, oncology inpatient costs increase and are at their peak. Patients with leukemia like Luis "had the highest mean total EOL cancer-related costs" at a staggering $197,676. [6]

Many of our clients unfortunately die, not necessarily because of initial poor prognosis, but because we could not navigate the bureaucratic immigration and health financing systems in time. Not only are these patients, their families and their providers directly harmed by these premature and expensive deaths but the

[4] Preussler, Jaime M et al. "Costs and cost-effectiveness of hematopoietic cell transplantation." Biology of blood and marrow transplantation : journal of the American Society for Blood and Marrow Transplantation vol. 18,11 (2012): 1620-8. doi:10.1016/j.bbmt.2012.04.001

[5] Laupacis, Andreas, Paul Keown, Nancy Pus, Hans Krueger, Beryl Ferguson, Cindy Wong, and Norman Muirhead. "A study of the quality of life and cost-utility of renal transplantation." Kidney international 50, no. 1 (1996): 235-242.

[6] Chastek, Benjamin, Carolyn Harley, Joel Kallich, Lee Newcomer, Carly J. Paoli, and April H. Teitelbaum. "Health Care Costs for Patients With Cancer at the End of Life." Journal of Oncology Practice. Web. 22 Mar. 2017. This is true whether the patient opts for hospice or not. When the patient does not opt to be in hospice, those costs are incurred in the form of visits to the emergency room and time spent in the intensive care unit. Furthermore, the patient then usually dies in the hospital.

inability for undocumented immigrants to participate in most clinical trials directly impacts health innovation and quality care for the rest of the population.

Clinical trials are essential for evaluating new treatment modalities, establishing new standards of care and, ultimately, improving and prolonging the lives of patients with serious illnesses. Nevertheless, rare disease clinical trials consistently have low rates of participation, especially when regarding patients from particular ethnic or racial, geographic, age, and other underserved demographic subgroups. The issue of clinical trial enrollment is viewed as foundational, lying at the heart of the clinical trial endeavor[7]. One-third of publicly funded trials require a time extension because they fail to meet initial recruitment goals[8]. Per a report from the Institute of Medicine, 40% of National Cancer Institute sponsored oncology trials failed to achieve minimum patient enrollment. [9]

A 2014, a research study on the Examination of Clinical Trial Costs and Barriers for Drug Development conducted on behalf of the Department of Health and Human Services cited difficulties in recruitment and patient diversity as major

[7] Murthy, V. H., Krumholz, H. M., & Gross, C. P. (2004). Participation in cancer clinical trials race-, sex-, and age-based disparities. Jama, 291(22), 2720-2726.
[8] Campbell M.K., Snowdon C., Francis D., Elbourne D., McDonald A.M., Knight R., Grant A. Recruitment torandomised trials: strategies for trial enrollment and participation study: the STEPS study. Health Technol. Assess. 2007;11:105. iii-ix.
[9] Institute of Medicine . National Academic Press; Washington D.C: 2010. Committee on Cancer Clinical Trials.

obstacles to conducting clinical trials in the United States."[10] According to the American Society for Clinical Oncology, a clinical trial system that enrolls patients at a higher rate produces treatment advances at a faster rate, and concurrent survival increases and mortality reductions in the cancer population.

In some of the cases where LegalHealth was able to help patients access insurance, the patients were able to participate in clinical studies which dramatically altered their lives as well as contributed to medical research. For example, Miguel, a 38-year-old with stage 4 melanoma, had an existing immigration history that we discovered deemed him eligible for public health insurance. Through our Medicaid advocacy efforts, Miguel was able to take part in one of the first immunotherapy clinical trials which led to a breakthrough in using immunotherapy to treat certain cancers. Miguel is now in remission and working to support his family. For others, like Vivian, we identified an immigration remedy which could be filed which also led to insurance eligibility. She is one of the only minority patients participating in a highly anticipated National Institute of Health trial comparing different forms of stem cell transplants for those who cannot find donor matches. Miguel and Vivian are the exceptions. They were able to

[10] Examination of Clinical Trial Costs and Barriers for Drug Development . Available at: https://aspe.hhs.gov/report/examination-clinical-trial-costs-and-barriers-drug-development

participate in the clinical trials because they were fortunate enough to have a team of doctors and lawyers working together for months. Many patients do not have that luxury or the time to wait.

This proposed resolution will help minimize the health inequalities faced by our immigrant population. As I've highlighted in my testimony, adequate insurance access will improve the lives of undocumented immigrants, their family and the community at large.