



# The Cancer Cliff

Addressing legal issues that stand  
in the way of cancer care.

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# THE CANCER CLIFF

## A NATIONAL CANCER LEGAL SERVICES NETWORK REPORT

### INTRODUCTION

When Laura was referred to a program that provides free legal services to people with cancer, she was a single mother with breast cancer, no income, and no medical insurance. Saddled with \$319,253 in medical bills, she faced bankruptcy. While Laura's doctors addressed her cancer, her attorney solved her financial dilemma. She received assistance in applying for Social Security Disability, which was subsequently approved. Laura was also advised to apply for Medicaid, which she did, but she never received a decision from the Medicaid office. Her attorney requested a fair hearing on her behalf and represented her. The Administrative Law Judge directed Medicaid to approve Laura for coverage dating back to November 2009 through August 2010, which would cover all of her medical bills.

One of the leading and most devastating causes of poor health and high costs in the American healthcare system is cancer. People living with cancer face a myriad of legal and economic challenges and may greatly benefit from legal services that mitigate these repercussions. Many struggle with insurance disputes, obtaining public benefits, housing, loss of employment, future care and custody planning of minor children, and estate planning.<sup>1</sup> The ramifications of cancer have a particularly disproportionate and destructive effect on uninsured,

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<sup>1</sup> Retkin, R., Brandfield, J., & Bacich, C. (2007). *Impact of legal interventions on cancer survivors*. Retrieved from [http://www.bc.edu/content/dam/files/schools/law\\_sites/library/pdf/content/tremblay\\_schulman/2007-01-00.Retkin%20et%20al.pdf](http://www.bc.edu/content/dam/files/schools/law_sites/library/pdf/content/tremblay_schulman/2007-01-00.Retkin%20et%20al.pdf)

low-income, and at-risk populations.<sup>2</sup> If you are poor and cancer strikes, there is no safety net to catch you, no savings account or access to resources to keep you from falling off the cliff.

The National Cancer Legal Services Network (NCLSN) was established to increase the availability of legal services on behalf of individuals living with cancer, like Laura. By connecting cancer patients with legal services, the NCLSN works to lift their legal burdens, allowing them to focus instead on their medical care and improving their quality of life.

The NCLSN was established in 2009 by LegalHealth, a division of the New York Legal Assistance Group, through a LiveSTRONG Foundation grant.<sup>3</sup> Its membership of 45 organizations includes medical-legal partnerships, non-profit legal aid organizations, private law firms, bar associations, cancer support and advocacy organizations, social workers, and patient navigator programs.<sup>4</sup> Not only does the NCLSN work to increase the availability of free legal services to people with cancer, but its members also advocate for low-income cancer patients at the national level.

The overarching aim of this White Paper is to help the reader understand: (1) the effect cancer has on low-income populations; (2) how increased access to legal services can help those living with cancer; and (3) the impact the NCLSN has on cancer patients and their families. Although the NCLSN has made great progress and has seen steady growth, there are still tremendous opportunities to expand the network to provide more services to cancer patients around the country.

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<sup>2</sup> (2007), Uninsured Present with more Advanced Cancer. *CA: A Cancer Journal for Clinicians*, 57(5), 257-258.

<sup>3</sup> New York Legal Assistance Group, LegalHealth, National Reach. (n.d.). Retrieved May 4, 2015, from <http://legalhealth.org/national-reach/nclsn/>.

<sup>4</sup> New York Legal Assistance Group, LegalHealth, National Reach. (n.d.).

## THE CONSEQUENCES OF CANCER

Cancer is the second leading cause of death in the United States (preceded only by heart disease), and the diagnosis rates are increasing.<sup>5</sup> It is predicted that, by the end of 2015, there will be an estimated 1,665,540 new cancer cases diagnosed and 585,720 deaths from cancer in the United States, meaning roughly 1,600 people will die each day from cancer.<sup>6</sup> Ultimately, half of all men and one-third of all women in the United States will develop cancer at some point in their lifetime.<sup>7</sup> While the 5-year survival rate for all diagnosed cancers has increased (68% from 2003-2009 compared to 49% from 1975-1977), the rate of cancer diagnosis – as well as the overall societal and individual costs of cancer – continue to increase.<sup>8</sup>

According to the National Cancer Institute, people who are from low socioeconomic backgrounds often bear a greater burden of cancer than the general U.S. population, experiencing cancer health disparities such as higher cancer incidence, prevalence, morbidity, and mortality.<sup>9</sup> Socioeconomic status often predicts whether a person has access to health insurance, certain occupations, education, and environmental toxins, all of which are associated with the risk of developing cancer and one's ability to survive it.<sup>10</sup>

One of the biggest predictors of health outcomes generally is whether a patient has health insurance. A review conducted by The Henry J. Kaiser Family Foundation in 2013 showed that

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<sup>5</sup> Cancer Facts and Figures. (2015). Retrieved from <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-044552.pdf>

<sup>6</sup> Cancer Facts and Figures. (2015).

<sup>7</sup> Cancer Facts and Figures. (2015).

<sup>8</sup> Cancer Facts and Figures. (2015).

<sup>9</sup> The National Cancer Institute, National Institute of Health, Cancer Health Disparities. (2008). Retrieved from <http://www.cancer.gov/aboutnci/organization/crhd/cancer-health-disparities-fact-sheet>

<sup>10</sup> The National Cancer Institute, National Institute of Health, Cancer Health Disparities. (2008).

those who are uninsured have many more hardships than those who have healthcare coverage.<sup>11</sup> For example, 25% of uninsured adults went without any healthcare because of the cost (compared to 4% of people who had coverage) and 55% lacked access to a facility where they could consistently receive medical advice and/or treatment.<sup>12</sup> Uninsured patients are also far less likely to get preventive care, including cancer screenings, and are less likely to receive necessary follow-up screenings after abnormal cancer tests.<sup>13,14</sup> Consequently, low-income, uninsured patients have an increased risk of being diagnosed in later stages of cancer than those with insurance and experience higher mortality rates.<sup>15,16,17</sup> Although the Affordable Care Act has created new insurance opportunities for those living with cancer, there are still many gaps in coverage for specialty care and certain medications.<sup>18</sup> Additionally, in states where Medicaid has not been expanded, many individuals are still unable to obtain affordable insurance.<sup>19</sup> Further, employer-sponsored healthcare coverage continues to decline.<sup>20,21</sup>

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<sup>11</sup> The Henry J. Kaiser Family Foundation, *The uninsured a primer 2013-4: How does a lack of insurance affect access to health care?* (2013, November 14). Retrieved from <http://kff.org/report-section/the-uninsured-a-primer-2013-4-how-does-lack-of-insurance-affect-access-to-health-care/>

<sup>12</sup> *The uninsured a primer 2013-4: How does a lack of insurance affect access to health care?* (2013, November 14).

<sup>13</sup> *The uninsured a primer 2013-4: How does a lack of insurance affect access to health care?* (2013, November 14).

<sup>14</sup> Rhodes, S., Hiller, K., Stolz, U., & Hays, D. (2012). *Cancer Screening—United States, 2010*, Centers for Disease Control. Retrieved from <http://www.cdc.gov/mmwr/pdf/wk/mm6103.pdf>

<sup>15</sup> Wilper, A.P., Woolhandler, S., Lasser, K.E., McCormick, D., Bor, D.H., & Himmelstein, D.U. (2009). Health Insurance and Mortality in US Adults. *American Journal of Public Health*, 99(12) 2289-2295.

<sup>16</sup> Simard, E.P., Fedewa, S., Ma, J., Siegel, R., & Jemal, A. (2012). Widening Socioeconomic Disparities in Cervical Cancer Mortality Among Women in 26 States, 1993-2007. *Cancer*.

<sup>17</sup> Institute of Medicine. (2009). *America's Uninsured Crisis: Consequences for Health and Health Care* (pp. 60-63). Washington, DC: National Academies Press.

<sup>18</sup> National Coalition for Cancer Survivorship, *The Affordable & Cancer Survivorship*. (n.d.). Retrieved June 3, 2015 from <http://www.canceradvocacy.org/news/the-affordable-care-act-cancer-survivorship-infographic/>

<sup>19</sup> National Coalition for Cancer Survivorship, *The Affordable Care Act & Cancer Survivorship*. (n.d.).

<sup>20</sup> Gould, E. (2012, December 5). Employer-sponsored health insurance coverage continues to decline in the new decade, Economic Policy Institute. Retrieved from <http://www.epi.org/publication/bp353-employer-sponsored-health-insurance-coverage/>

<sup>21</sup> Gould, E. (2012, February 23). A decade of declines in employer-sponsored health insurance coverage, Economic Policy Institute. Retrieved from <http://www.epi.org/publication/bp337-employer-sponsored-health-insurance/>

For patients with or without insurance, cancer is an expensive disease. The National Institute of Health estimated that in 2009 the overall cost of cancer was \$217 billion: \$87 billion for direct medical costs and \$130 billion for indirect mortality costs (costs of decreased economic productivity due to premature death along with lost wages due to medical disability while in treatment or caring for a loved one).<sup>22</sup> The NIH projects that by 2020, direct medical costs alone will be at least \$158 billion, an increase of 27% over ten years.<sup>23</sup> Soaring medical expenses can translate into a high financial burden for individuals living with cancer and their families, especially those with lower incomes. A study focusing on colon cancer patients found that 31% reported a high or very high financial burden, with 23% reporting the accrual of treatment-related debt averaging \$26,800.<sup>24</sup> Additionally, an individual's out-of-pocket costs can add up very quickly; in 2007, the mean annual expenditures on all services were \$16,910.<sup>25</sup> The overall severity of a financial burden depends on many variables such as the type of cancer, when the cancer was discovered (early detection improves both health prognosis and financial implications for the individual), the type of treatment options available to the individual, and amount of insurance coverage.<sup>26</sup>

The costs of cancer can have a devastating impact on patients and their families.

Treatment costs negatively impact a patients' ability to cover living expenses, such as housing

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<sup>22</sup> Managing the Costs of Your Cancer Treatment, American Cancer Society. (2014). Retrieved from <http://www.cancer.org/treatment/findingandpayingfortreatment/managinginsuranceissues/the-cost-of-cancer-treatment>

<sup>23</sup> Cancer Costs Projected to Reach at Least \$158 billion in 2020. (2011, January 12). Retrieved from <http://www.nih.gov/news/health/jan2011/nci-12.htm>

<sup>24</sup> Shankaran V., Jolly, S., Blough, D., & Ramsey S.D. (2012). Risk factors for financial hardship in patients receiving adjuvant chemotherapy for colon cancer: a population-based exploratory analysis. *Journal of Clinical Oncology*. 30(14):1608-14.

<sup>25</sup> Short, P.F., Moran, J.R., & Punekar, R. (2011). Medical Expenditures of Adult Cancer Survivors Aged <65 Years in the United States. *Cancer* 117(12) (cancer increases the risk of high out-of-pocket expenditures).

<sup>26</sup> Ramsey, S.D., Fedorenko, C.R., Snell, K.S., Kirchhoff, A.C., Hollingworth, W., & Blough, D.K. (2011). ASCO Annual Meeting Session: Cancer diagnosis as a risk factor for personal bankruptcy. Retrieved May 6, 2015, from <http://meetinglibrary.asco.org/content/82633-102>

payments and groceries. One 2010 survey of cancer patients found that almost 30% reported dealing with bill collectors.<sup>27</sup> In another survey from 2014, 27% of cancer survivors reported at least one financial problem, and 37% reported having to modify their employment due to cancer.<sup>28</sup> This survey of nearly 1,600 cancer survivors found that women, young survivors, racial/ethnic minorities, and the uninsured were disproportionately affected.<sup>29</sup>

These costs can also negatively impact a patient's focus on recovery, according to a survey conducted by the Association of Oncology Social Work.<sup>30</sup> The findings showed that 54% of those handling a major financial burden struggled to afford treatment, while 29% of patients delayed prescriptions due to financial pressures and 22% skipped doses of their medication.<sup>31,32</sup> In another study, where 9% of the entire patient population decided to forego a recommended cancer treatment due to cost, this percentage increased to 25% for individuals with an income of less than \$40,000.<sup>33</sup>

While the physical and financial burdens of cancer are overwhelming for most cancer patients, the psychological and emotional impact that a cancer diagnosis can have on an individual and their family cannot be overstated. Studies have shown that patients with financial hardships due to cancer are more likely to rate their physical and mental health as poor, as

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<sup>27</sup> Mellace, J. (2010, April/May). The Financial Burden of Cancer Care. *Social Work Today*. (10, 2) Retrieved from <http://www.socialworktoday.com/archive/032210p14.shtml>

<sup>28</sup> Whitney, R.L., Bell, J., Reed, S., Davis, A., Lash, R.S., Kim, K., ... Joseph, J.G. (2014). Palliative Care in Oncology Symposium Session: Work and Financial disparities among adult cancer survivors in the United States. Retrieved May 6, 2015, from <http://meetinglibrary.asco.org/content/137778-153>

<sup>29</sup> Whitney (2014).

<sup>30</sup> Mellace (2010).

<sup>31</sup> Mellace (2010).

<sup>32</sup> See also Zafar, S., Peppercorn, J., Schrag, D., Taylor, D., Goetzinger, A., Zhong, X., & Abernethy, A. (2013). The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing Out-of-Pocket Expenses and the Insured Cancer Patient's Experience. *The Oncologist*, 381-390 (some patients will avoid filling their prescriptions altogether).

<sup>33</sup> Markman, M. & Luce, R. (2010). The Impact of the Cost of Cancer Treatment: An Internet-Based Survey. *American Society of Clinical Oncology* (6:2).



compared to those who did not have financial hardships.<sup>34</sup> Cancer patients with major financial challenges are also likely to suffer from depression and anxiety.<sup>35</sup> A 2010 survey of cancer patients with breast, lung, prostate, and colon cancer found that 39% of individuals with a yearly income of less than \$40,000 reported the financial costs of treating their cancer had caused a “large amount of distress,” compared to 19% of patients overall.<sup>36</sup>

It has been demonstrated that cancer patients and survivors are likely to suffer social, legal, and economic problems.<sup>37</sup> The need for social support services, namely legal services, to help patients advocate for themselves, access the services to which they are entitled, and re-enter the job market is critical. These services are especially important because the stabilization of an individual’s financial and legal needs could potentially lead to an overall improvement of cancer prognosis and life expectancy.<sup>38</sup>

#### **LEGAL ASSISTANCE AS A MEANS TO ADDRESS CANCER’S IMPACT**

Ideally, when individuals are diagnosed with cancer, they should be able to focus fully on their health treatment and spend more time with loved ones. But often such is not the case. Cancer patients often have to deal with many hardships throughout the course of their illness, including burdensome legal problems.

Low-income people in general have to navigate complex systems and as a result, may have a number of legal needs. Nationally, 47% of low-income and 52% of moderate-income

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<sup>34</sup> See, e.g., Fenn, K. M., Evans, S.B., McCorkle, R., DiGiovanna, M.P., Puzstai, L., Sanft, T., ... Chagpar, A.B. (2014). Impact of financial burden of cancer on survivors' quality of life? *Journal of Oncology Practice*, JOP-2013.

<sup>35</sup> Mellace (2010).

<sup>36</sup> Markman (2010).

<sup>37</sup> See, e.g., Valdivieso M., Kujawa A.M., Jones T., Baker L.H. (2012). Cancer Survivors in the United States: A Review of the Literature and a Call to Action. *Int J Med Sci* 9(2):163-173.

<sup>38</sup> Zevon, M.A., Schwabish, S., Donnelly, J.P., Rodabaugh, K.J. (2007). Medically Related Legal Needs and Quality of Life in Cancer Care: A Structural Analysis. *Cancer* 109(12): 2600-2606.

households have at least one unmet legal need, and 14% of low-income households have three or more unresolved legal disputes. Among the low-income population, over 75% of legal needs/disputes are addressed without the help of an attorney.<sup>39</sup> Most of these needs remain unresolved, naturally resulting in more complications, financial issues, and stress for those involved or affected. Legal needs are further exacerbated by a cancer diagnosis, treatment, and side-effects of the illness and medication, not only for the cancer patients but also their families.

For example, Lillian was referred to The Family Center (TFC), a NCLSN member in New York, by Calvary Hospice after her mother died from stomach cancer. At the time, Lillian was 21 years old, a full-time college student and worked part-time at Costco. She was struggling with taking care of her brother, grieving for her mother, and keeping her own life on track. She had many questions and concerns. An attorney with TFC visited Lillian at her home and developed a plan to address Lillian's emerging problems with housing, benefits (Social Security) and guardianship of her brother. With a great deal of advocacy and continued recognition of her fragile situation, the lawyer met her wherever convenient to carry out the legal work, including at her place of employment. Ultimately, the FC attorney helped Lillian regain control and responsibility of her mother's apartment, secured benefits for her brother so that Lillian did not have to quit school to work more, and helped her obtain guardianship for her brother.<sup>40</sup>

The legal needs of low-income cancer patients and their families are wide-ranging. They include: insurance issues, patient's rights, employment, finances (including public benefits), advance directives (healthcare proxies, wills & advance planning), permanency planning, and immigration-related issues.

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<sup>39</sup> Paul, E., Fullerton, D.F., Cohen, E., Lawton, E., Ryan, A., & Sandel, M. (2009). Medical-legal partnerships: Addressing competency needs through lawyers. *Journal of Graduate Medical Education*, 1(2), 304-9.

<sup>40</sup> National Cancer Legal Services Network, Our Impact. (n.d.). Retrieved May 6, 2015 from <http://www.nclsn.org/impact-our-stories/>

### *Insurance and Patient's Rights*

Patients have many concerns about their experience in the healthcare system. Their chief concern is ensuring that their care will be covered. If they are uninsured, this means finding a way to become insured. Even when they are insured, cancer patients are burdened with a wide variety of medical and hospital bills for their treatments. They are more likely to have disputes with their insurance companies on what portions of their bills will be covered. Considering that these disputes are often daunting for most people unfamiliar with health insurance law, legal assistance can provide many potential benefits. Patients also have concerns about their discharge rights, nursing facility regulations, rights of family members, long-term care issues, and family law matters, among many others.

### *Employment*

Unfortunately, working during cancer treatment is a painful reality for many Americans, especially those who are struggling financially. Patients who have employer-sponsored health insurance need to maintain employment to continue to be covered under the employer plan, a situation commonly known as “job lock.” And unlike most similarly wealthy countries, the United States has no nationally implemented standard for paid sick leave. Moreover, cancer survivors face higher rates of employment discrimination and unemployment post-treatment.<sup>41,42,43</sup> Other common employment legal needs include employee rights, insurance

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<sup>41</sup> Mehnert, A. (n.d.). Employment and work-related issues in cancer survivors. *Critical Reviews in Oncology/Hematology*, 77(2):109-130.

<sup>42</sup> de Boer, A.G.E.M., Taskila, T., Ojajarvi, A., van Dijk, F.J.H., & Verbeek, J.H.A.M. (2009). Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression. *JAMA*, 301(7):753-762.

<sup>43</sup> Jagsi, R., Hawley, S.T., Abrahamse, P., Li, Y., Janz, N.K., Griggs, J.J., ... Katz, S.J. (2014). Impact of adjuvant chemotherapy on long-term employment of survivors of early-stage breast cancer. *Cancer* 120(12):1854-62.

rights, and disability.<sup>44</sup>

For working individuals, especially those with few economic resources, a cancer diagnosis can have many negative implications for their career and employment status. Cancer patients have to struggle with ways to maintain their current employment standing while receiving treatment. Many cancer patients are forced to miss weeks, if not months, of work depending on their prognosis and treatment options. They are more susceptible to being laid-off and running into disputes with their employers about paid sick leave. Access to legal assistance to help with these problems can be advantageous to a cancer patient's employment standing, resulting in more financial and emotional stability.<sup>45</sup>

### *Financial*

Common financial legal needs include monetary planning, Social Security issues, housing matters, pensions, tax implications, investment and ownership issues, and benefits. A cancer diagnosis causes many people to struggle to maintain a steady income and many are unable to pay for basic necessities such as food, heat, or housing. These matters make confronting a cancer diagnosis even more difficult and make it challenging to stay on track with treatment. Legal services can help alleviate some these matters by advocating for clients to maintain their benefits and by setting up systems to ensure that their bills are paid.

For example, an oncology patient was referred to the Legal Aid of Nebraska Medical Legal Partnership Project, a NCLSN member, because she had been denied Social Security Disability benefits despite clearly meeting requirements. The attorney contacted the local Social

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<sup>44</sup> Mehnert, A., de Boer, A., & Feuerstein, M. (2013). Employment challenges for cancer survivors. *Cancer*, 119(11 suppl):2151-2159. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/cncr.28067/epdf>

<sup>45</sup> Wolf, D. (2009). Know Your Legal Rights in the Workplace. *COPING with Cancer*. Retrieved from [http://legalhealth.org/wp-content/uploads/2012/07/coping\\_with\\_cancer.pdf](http://legalhealth.org/wp-content/uploads/2012/07/coping_with_cancer.pdf)

Security office and determined that the client was being denied because her payroll records indicated that she was still working. After speaking with her employer, the attorney discovered that although she had stopped working at least six months prior, she was receiving a pay check because her fellow employees were donating their sick and vacation time to her. After providing proof of this to Social Security, the decision was reversed and she was granted disability benefits.

### *Advance Planning*

Common estate issues include inheritance laws/disputes, distribution of property and assets, probate issues, credit cards and responsibility of payment, funeral home planning, and child custody disputes.<sup>46</sup> Inheritance issues and wills are especially important for cancer patients to resolve since they might not survive their illness. They will have to arrange for the distribution and allocation of their assets along with ensuring that their families can pay their funeral costs and medical bills. Legal assistance in these situations can put terminally ill cancer patients at ease in their final moments, knowing their family will be taken care of in their absence.

In one case, a 21-year-old client was referred to Family Legal Assistance, a medical-legal partnership between the Public Law Center and CHOC Children's Hospital in Orange County, California, and a NCLSN member. The client had been in treatment since she was first diagnosed with cancer at the age of 16, while she was pregnant. Her cancer had progressed, and she wanted to ensure that her mother would have authority to care for her child if the client were not available, as the child's father had never been a part of the child's life. Through Family

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<sup>46</sup> Retkin, R., Rodabaugh, K., & Mochizuki, T. (2011). Cancer patients, survivors and their families. In Tyler, E.T., Lawton, E., Conroy, K.N., Sandel, M., & Zuckerman, B. (Eds.), *Poverty, health and law: Readings and cases for medical-legal partnership* (p. 400). Durham, NC: Carolina Academic Press.

Legal Assistance, a pro bono attorney filed for a stand-by guardianship on behalf of the grandmother, which was granted the week that the client passed away.

### *Immigration-Related Issues*

Cancer patients come from many different backgrounds and face a variety of legal issues, some more complex than others. Legal issues surrounding immigration, temporary visas, and immigrant access to healthcare can be particularly challenging and warrant attorney involvement. For example, Diana was referred to NCLSN member Cancer Legal Line (CALL) by her social worker at the University of Minnesota. Diana needed a lifesaving bone marrow transplant and her chances of a full recovery were over 95% if she had a perfect sibling match as a donor. She did in her younger brother Eduardo, but he was denied a visa to enter the United States from Ecuador. CALL enlisted help from a team of volunteer attorneys at the Fredrikson & Byron law firm who, along with help from Senator Al Franken's office, expedited the appeal on humanitarian grounds. The appeal was granted and within 14 days, Eduardo was on his way to help save Diana's life.

Cancer alone makes patients vulnerable. Simultaneously coping with cancer and a serious legal matter can have catastrophic effects on patients and their families. The NCLSN aims to help clients avoid and overcome these consequences.

### **THE NATIONAL CANCER LEGAL SERVICES NETWORK**

The NCLSN has become a resource for patients, attorneys and healthcare providers across the country. Through its website, the NCLSN provides an online, comprehensive guide to existing cancer legal services. The directory helps patients find legal assistance and also allows the NCLSN to identify locations where additional legal resources are needed to help low-income

and at-risk populations dealing with cancer. In addition, the website has technical assistance resources available for new cancer legal services providers, includes important news on legislative developments that affect cancer patients, and has training materials for healthcare providers and patient navigators.

The NCLSN holds conference calls so that members can present their work, devise ways to improve cancer legal services, and discuss how to solve recurring client issues. The NCLSN has allowed lawyers working with cancer patients to share their experiences and communicate with one another about their practices. It has also cultivated an interest from attorneys who want to practice public interest law to help individuals with cancer. The NCLSN works collectively to research the impact of cancer legal services, provides support to members and interested organizations, and advocates for policy changes to ease the legal and societal burdens low-income experienced by cancer patients.<sup>47</sup>

Furthermore, the NCLSN helps attorneys assist their clients with their respective legal issues. Attorneys refer each other to published articles and studies about the benefits legal assistance can provide to cancer patients, training materials and presentations specifically designed to help lawyers with patients, employment resources for attorneys who may be unfamiliar with employment laws and employee rights, directories for attorneys unfamiliar with cancer terminology and medical information, and resources and contacts for attorneys who wish to form their own cancer legal services program.<sup>48</sup> Through the NCLSN, member organizations are enriched and presented with the tools they need to provide the best possible legal assistance to their present and future clients.

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<sup>47</sup> Retkin (2007).

<sup>48</sup> National Cancer Legal Services Network, Resources for attorneys. (n.d.). Retrieved September 5, 2014, from <http://www.nclsn.org/resources/resources-for-attorneys/>

## THE NCLSN – IMPACT

The work being done by the NCLSN and its member organizations has a profound impact on patients and their families. The NCLSN resolves complicated legal issues for cancer patients and also enhances the delivery of healthcare services by helping doctors to become advocates for their patients.<sup>49</sup>

### *Impact on Patients*

The primary objective of the NCLSN is to help cancer patients resolve their legal issues so that they can obtain the necessary treatment and focus primarily on their health, family, and overall wellbeing. A survey of cancer patients who received legal assistance through a NCLSN member, LegalHealth, yielded auspicious results: 75% of patients interviewed said legal assistance reduced stress, 50% reported that receiving legal assistance had positive ramifications on their families and loved ones, 45% said legal assistance positively affected their financial standing, and 30% of participants reported that legal assistance helped them maintain their respective treatment regimen.<sup>50</sup>

The NCLSN's impact is demonstrated by Mary's story. Mary was diagnosed with an aggressive form of breast cancer and her oncologist offered her participation in a clinical trial using a study drug in conjunction with standard of care chemotherapy. However, Mary's insurance company denied the preauthorization needed for her to enroll in the trial and begin treatment. Mary and her oncologist's office filed an internal appeal and coverage was again denied. Mary was nearing the time to begin chemotherapy, and she was disappointed and frustrated that her insurance company was denying her access to the drug treatment option. At

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<sup>49</sup> New York Legal Assistance Group, LegalHealth, National Reach. (n.d.).

<sup>50</sup> Fleishman, S.B., Retkin, R., Brandfield, J., & Braun, V. (2005). The attorney as the newest member of the cancer treatment team. *Journal of Clinical Oncology*, 24(13):2123-2126.



this point, Mary was referred to the Cancer Legal and Advocacy Services Project (CLASP) in Syracuse, New York, a NCLSN member. CLASP represented Mary on an expedited external appeal, submitting additional records, pertinent medical literature, and other supporting documentation. Three days later, the insurance company reversed its decision, finding that participation in the study was likely to benefit Mary in the treatment of her disease. Mary's oncologist quickly set up her participation in the trial.

The NCLSN also aims to help patients help themselves. Legal assistance organizations help their clients prepare for potential situations by providing them with the skills and confidence they need to handle their basic financial and legal issues. Research conducted by various medical-legal programs showed that patients who received legal services became better advocates for themselves.<sup>51</sup> By helping people advocate for themselves, legal services empower cancer patients to face and conquer their challenges.

### *Impact on Healthcare Professionals*

The NCLSN and its member organizations have also been credited with enhancing the delivery of healthcare services by educating and assisting healthcare professionals. When an attorney acts as a part of the healthcare team, the doctors are able to focus on a patient's health and are not burdened with issues outside of their professional reach. Additionally, legal professionals can take part in advising and educating doctors, social workers, and oncologists about some of the laws and the best ways for them to help their future patients with legal issues. As Randy Retkin, the Director of LegalHealth states, "There are many benefits to multidisciplinary collaboration... one includes allowing oncology specialists the opportunity to

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<sup>51</sup> Schulman, D.I., Lawton, E., Tremblay, P.R., Retkin, R., & Sandel, M. (2008). Public Health Legal Services: A New Vision. *Georgetown Journal on Poverty Law & Policy*, 15(2008): 729-780.

enrich their practice by gaining knowledge of the various legal and mental health issues associated with cancer. For oncological social workers, the availability of legal services allows them to focus on their primary mission of addressing their clients' psychological needs."<sup>52</sup>

Healthcare institutions and practices can benefit financially when their patients are not burdened with various legal issues. Patients who are dealing with legal issues may miss medical appointments and treatment because they are experiencing anxiety or are consumed with their legal matter. Access to legal services enables clients to receive a higher level of medical care; by having access to treatments, transplants, and other surgical procedures that may have been denied without legal intervention, cancer patients are better able to receive the monitoring and treatment they need to possibly save or prolong their lives. Furthermore, by assisting clients in obtaining coverage, legal services help to move uncompensated care paid for by the hospital to compensated care paid for by insurance companies.<sup>53</sup> This model creates a mutually advantageous result for both the patient and healthcare institution.

NCLSN supporter Kerry Rodabaugh, MD, based out of the University of Nebraska Medical Center, described the impact of cancer legal services on doctors like herself: "Many nonmedical issues can arise after a cancer diagnosis that hinder medical treatment – whether it's access to healthcare, living conditions, or employment and financial issues. Often these issues are something a doctor just cannot help their patient with, and many times can be far too overwhelming for a doctor to address. Making legal services available to health care providers gives us an invaluable resource with which to help our patients."<sup>54</sup>

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<sup>52</sup> Retkin (2007).

<sup>53</sup> Boyle, J., & Chiu, A. (2009). Financial Impact Study of LegalHealth Services to New York City Hospitals. Retrieved from [http://legalhealth.org/wp-content/uploads/2012/07/cost\\_benefit\\_final\\_report.pdf](http://legalhealth.org/wp-content/uploads/2012/07/cost_benefit_final_report.pdf)

<sup>54</sup> National Cancer Legal Services Network, Our Impact. (n.d.). Retrieved September 10, 2014 from <http://www.nclsn.org/holistic-patient-treatment/>

## **CONCLUSION**

The NCLSN is dedicated to improving the lives of those living with cancer. Through direct work, educational efforts and advocacy, the NCLSN's multidisciplinary coalition helps to alleviate the legal and economic consequences of cancer so that those affected may focus on their medical care and quality of life. The NCLSN supports the efforts of individuals and organizations focused on meeting the legal needs of the cancer-affected community. It augments the voice of disparate services, creates a forum for established and nascent legal advocacy groups, and facilitates the development of similar programs.

While the positive effect of the NCLSN's work is evident, many low-income cancer patients still need legal assistance. The hope is that, with increased support and funding, the NCLSN can eventually reach more people and expand its services. As we move forward, we aim to enhance the impact of the NCLSN's work and maximize our efforts to alleviate the legal and financial burdens of cancer for low-income patients across the country.