Introduction

This policy attempts to address two key challenges facing the state of Nebraska. The first is the increased incidence of pediatric tumors throughout the state. The second is a review of the impacts of the disease on the 80% of children who will survive, their families and the state.

The Incidence of Pediatric Cancer in the United States

Pediatric cancer continues to be the number one cause of death due to disease in the United States of America for children between infancy and 14 years of age. More children die from pediatric cancer than from asthma, cystic fibrosis and AIDS combined. Childhood cancer rates have been slowly increasing over the last several decades, and the reason for this is unknown.

Figure 1: Incidence rates for pediatric cancer in the United States, 2010

Source: SEER: Surveillance, Epidemiology and End Results. NPCR: National Program of Cancer Registries
Pediatric Cancer in Nebraska: Policy Implications

In the United States of America, the incidence (number of new cases diagnosed during a given time) of pediatric cancer as determined by The Surveillance, Epidemiology and End Results data from 2007-2011 is 17.3 per 100,000 children ages 0-19 years. In 2010, the incidence rate of pediatric cancer in Nebraska (18.6 per 100,000 children ages 0-19 years) ranked fifth in the country as shown in Figure 1.

Higher rates of pediatric tumors in the Northeast of the country have been identified for a number of years. Although one direct cause has never been identified, researcher have hypothesized that better reporting of cases of pediatric cancer may play a role. Furthermore, environmental toxins such as radiation may also have an impact on the overall incidence of pediatric cancer in the Northeast. The regional disparity between incidence rates in Wyoming, South Dakota, Iowa and Kansas when compared to Nebraska is also unknown.

The Incidence of Pediatric Cancer in Nebraska

The incidence of pediatric cancer in Nebraska has exceeded national incidence rates since 2007, and continues to increase as detailed in Figure 2.

**Figure 2: Pediatric Cancer Incidence and Mortality Rates from 1990 – 2011**

Source: Data provided by the Nebraska Cancer Registry. From 2009 to 2011 the incidence rate rose from 18.5 per 100,000 to 19.8 per 100,000 children aged between 0 and 19 years.

More investigation is needed to examine the patterns of childhood cancer in Nebraska over time. Although more information has been discovered regarding the causes of certain pediatric cancers, the cause of most childhood cancer remains elusive. The genetics of the family combined with environmental factors most likely play a role in the cause of the majority of childhood cancers.

Within the state of Nebraska, further study is needed to examine whether there are locations that have a higher incidence of pediatric tumors than what would be predicted.
As outlined in Figure 3, data from the Nebraska Department of Health and Human Services was used by Children’s Hospital and Medical Center in an attempt to identify areas of the state where higher rates of pediatric cancer occur. When population data from the 2000 census was applied to known cases of pediatric tumors diagnosed at Children’s Hospital and Medical Center and at The Nebraska Medical Center from 2008-2012, a number of counties revealed an incidence greater than that for the state as a whole. The cause of this is unknown, but multiple influences such as family genetics and environmental factors may be involved.

As with all statistics involving rare diseases, these data should be interpreted cautiously. Pediatric cancer is a rare event, accounting for only 2% of all cancer in the country. In states with lower overall populations, it is often difficult to validate rare disease data given the low numbers of possible patients who can be affected. For these reasons, specific data within individual counties can vary greatly from year to year, making validation difficult.

Statistical methods for disease mapping have been developed to address these methodological issues. Further study of the distribution of pediatric cancer across the state is needed, utilizing these advanced statistical techniques. Analysis using simple rates for each county can be highly unstable for counties with small population size. Thus, simple descriptive statistics at the county level are extremely difficult to interpret and can lead to incorrect conclusions. Advanced geospatial statistical mapping methodologies are needed to study the distribution of disease in this setting of a rare disease like pediatric cancer, particularly in geographic regions with small population size.\(^6\)
Policy Implications regarding Pediatric Cancer

In the 1950s childhood cancer was almost always fatal. Today, through advances in research that have led to better diagnostics and improved treatments, almost 80% of children with the most common types of pediatric cancer will survive their disease. While this comes as welcome news, long-term survivors of childhood cancer can have impacts on their health and wellbeing that should be considered in future planning.

The toll of therapy for pediatric cancer is not arbitrary and includes both financial and personal costs that are often compounded for families living in rural communities. The majority of survivors of childhood cancer have chronic medical conditions for the remainder of their lives. Impacts can be seen on their physical, psychological and social wellbeing, which in turn can have their impacts on their future health. These effects can have consequences on their ability to finish an adequate education, obtain or maintain employment and have a family. All of these consequences can have future impacts on the state of Nebraska.

In order to plan effectively, more will need to be known about the specific needs of childhood cancer survivors and their families. This information could help shape an early intervention program, which could alleviate some of the damage caused by the disease and the treatments. By identifying the stressors and risks for these children early in the process, more support can be provided to aid in their overall success. Any intervention program would need to incorporate expertise in cognitive, behavioral, physical, developmental and social realms to ensure all the needs of the children and their families are met. Issues such as those experienced by survivors of pediatric cancer will need to be addressed by every state as an investment in their future. Nebraska has the opportunity to be a leader for the nation in the development and implementation of such a program that could function as a model for other states.

While intervening early for survivors represents a crucial step for those affected by pediatric cancer, opportunities also exist to further understand the increased rate of childhood cancer in Nebraska. More data could be collected regarding the environmental factors that could play a role in the development of pediatric tumor. Furthermore, an analysis of the genetic composition of families living in areas of the state where high rates of pediatric cancer occur may yield new information about mutations that make pediatric tumors more likely. This data could then be shared with other state and national groups to have a wider impact for children at risk for childhood cancer.

For children in Nebraska, the combined group of pediatric hematologists and oncologists at The Nebraska Medical Center and Children’s Hospital and Medical Center in Omaha represent the one location for comprehensive care. This one site system differs from the majority of states in the nation where patients with childhood cancer can be evaluated and treated in multiple locations. For the people of Nebraska, having one-site functions as a both strength and a challenge to families dealing with this disease. As a strength, any future questions regarding the incidence, diagnosis, management and treatment of children with cancer can be answered by one multi-disciplinary group of researchers in one location. However, for patients and families that live in rural Nebraska traveling to Omaha can be a significant burden.

More information should be collected regarding the impact on the family of cost of travel, lost time at work, impact on future employment, and stress which can possibly lead to separation or divorce. All these factors may represent threats to the family that could also have impacts on the state.
The access to comprehensive pediatric medical care can be problematic in states with large rural populations. For these reasons, investigations in mediating these issues should be a focus of future planning. Possible solutions that could be explored include utilizing the resources of tele-medicine to assist local caregivers in the management of patients, or investing in improved continuing medical education regarding the management of children with chronic medical conditions for physicians, physicians assistants and advanced practice nurse practitioners.

**Conclusion**

This analysis of the incidence of pediatric cancer in Nebraska reveals that cancer rates continue to rise, and the cause of this increase is unknown. Although 80% of children diagnosed with cancer will survive, the majority of those children survive with chronic medical conditions that can have a profound impact on their future. Opportunities exist to further understand the impact of pediatric cancer on the state of Nebraska at multiple levels, including the child, the family and the community. Any knowledge gained about the disease and its impact is likely to be generalizable to other chronic pediatric conditions and serve as a model to other states in the nation.

**References**


