



Improving Access to Care for Bleeding Disorders Patients In Nevada

A White Paper Written by:

Amber Federizo, APRN, FNP-BC

Hemostasis Board Certified

Improving Access to care for Bleeding Disorders Patients in Nevada

Introduction

Bleeding Disorders: Bleeding disorders are serious, incurable, complex, costly, rare, and potentially life-threatening genetic conditions which result in a deficiency of a specific clotting protein required to effectively stop bleeding. Occasionally, an individual can acquire a bleeding disorder through other medical conditions. Patients with bleeding disorders may suffer from intracranial hemorrhage, joint bleeding, heavy periods, frequent and heavy nosebleeds, gastrointestinal bleeding, pain, and hematomas that can interfere with full activities of daily living. Over 1000 patients are affected by bleeding disorders in the state of Nevada.

Comprehensive Care: For the past 40 years, the federal government has supported a network of over 130 regionally organized Hemophilia Treatment Centers (HTCs). These HTCs provide coordinated team-based 'comprehensive care' per federal Health Resources and Services Administration (HRSA) goals, Centers for Disease Control Surveillance, and additional national organization guidelines. Federally recognized centers provide comprehensive services including diagnosis, treatment, rehabilitation coordination, education, counseling, outreach and low-cost pharmacy services utilizing federally discounted prices.

At each comprehensive visit, a patient is evaluated by the core team which includes at a minimum a provider, a nurse, physical therapist, and social worker. These visits assess socioeconomic, physical, and mental barriers or support that affect patients' everyday functioning. Similar to a medical home model, coordination of care, referrals, and treatment are coordinated between the bleeding disorders clinician and the patient's primary care and other specialty care providers. This comprehensive HTC care is provided to patients regardless of insurance. Financial assistance is provided through sliding scale self-pay options and through partnership with the local chapter of the National Hemophilia Foundation. Patients are provided with critical access to dental care, orthopedic care, medication support, and referrals and care coordination with other consultants as needed such as obstetrician/gynecologists, hepatologists, and others.

Currently, there is only one federally recognized hemophilia treatment center in Nevada. The Hemostasis and Thrombosis Center of Nevada's founding program director has over 20 years of experience in the care of affected Nevadans. The center's co-founding medical director is the only hemostasis board-certified family practice nurse practitioner in the state. The center's social worker and physical therapist have received additional training in bleeding disorders care. This comprehensive team serves the entire state, through a hub location in Las Vegas and at six long established sites state-wide: Elko (2 sites – including an Urban Indian Health Center), Ely, Reno, Winnemucca, and Owyhee (Duck Valley Indian Reservation).

Research: CDC studies have shown that males with hemophilia treated in a federally recognized hemophilia treatment center experience a 40% reduction in both mortality and bleed-related morbidity including hospitalizations and costs (Soucie, Nuss, Evatt, Abdelhak, Cowan, Hill, Kolakoski, & Wilbur, 2000). Additionally, patients treated in a federally recognized

treatment center incur fewer overall costs and losses due to hospitalizations and unemployment (Soucie, et al., 2001). Despite the impact of federally recognized HTC on health status, quality of life and costs, Nevadans with bleeding disorders encounter difficulty accessing care from HTCs due to insurance barriers, chiefly narrow health plan networks. Some health plans decline to contract with the HTC. Other health plans, while they agree to contract, often delay, deny, or modify HTC treatment plans. The impact is a higher risk of lower quality of life, shortened lifespan and higher costs when HTC access is denied.

Surveillance and health outcomes: Federally recognized HTCs are required to participate in national initiatives for continuous health outcomes monitoring – to identify emerging threats to the blood supply (i.e. Zika, West Nile Virus) and to track disease progression. These include partnerships with the CDC and Healthy People 2020. For the past 20 years, all HTCs conduct CDC surveillance that extensively monitors key metrics including bleeding disorder complications, blood safety, and health services utilization. These CDC data are used to measure Healthy People 2020 objectives for the nation’s bleeding disorders population. All federally recognized centers also participate in national patient satisfaction surveys, and the American Thrombosis and Hemostasis Network’s national dataset which further monitors trends in achieving national health outcomes.

Quality assurance and regional oversight: Quality of federally recognized center services is continuously assessed by Regional Directors/Principal Investigators of HRSA and CDC grants who oversee the HTCs in their geographic catchment area. Each center must work towards the completion of over 25+ federal HRSA objectives, and CDC surveillance enrollment expectations. The objectives are embedded as contractual obligations between the Regional “Core Center” and the individual HTCs within the region. Failure to provide care per HRSA and National Hemophilia Foundation guidelines, and failure to make adequate progress across these HRSA and CDC objectives can result in revocation of grant funding. Non-federally recognized hematology practices are under no similar obligation and oversight. Federal recognition is the highest form of quality recognition given the specificity of the criteria. In bleeding disorders, federal recognition affords access to national and international research, and a professional network of bleeding disorders experts not available to non-federally recognized centers.

Barriers to care for Nevadans with Bleeding Disorders

Access barriers due to shortages in the hematology/oncology physician workforce:

Bleeding disorder expertise is theoretically presumed to be encompassed in a hematology/oncology fellowship training. However, these fellowships typically prioritize oncology due to higher salaries that oncologists obtain under US health care reimbursement which favors inpatient and procedure-based care, whereas most of hematology is outpatient and preventative. The number of fellowships that allow for the pursuit of advanced education in bleeding disorders is staggeringly low (only 8 programs in adult hematology in the United States)⁴. Given the more lucrative nature of oncology, few private practice oncologists have focused their training in hematology. In practice, this leads to an insufficient patient base size to obtain and maintain the ongoing expertise needed in the fast-evolving research of malignant and

non-malignant hematology. Due to this overlap in the education of oncology and hematology, health plans expanding their networks assume the inclusion of adult and pediatric oncology/hematologists is sufficient to provide high-quality bleeding disorders care. It is not.

Access barriers due to narrow health plan networks: Many Nevadans with bleeding disorders wish to maintain their care at the HTC to obtain expert rare disorder care they need. To do so, many patients elect to access the HTC out-of-network or self-pay. However, their health plans often decline to cover their medications due to out of network provisions of their insurance policies. While federally recognized HTC patients have same day appointment availability for evaluation and treatment when affected Nevadans are required to utilize preferred provider networks they often encounter delays in accessing outpatient care. The pain associated with internal bleeding is so acute that many have no recourse but to seek emergency department care, which could be avoided with HTC access. In the bleeding disorder population, difficulties in obtaining same day appointments from a preferred provider network can be significant owing to the mistaken belief that oncology patients are a priority for evaluation. This can result in catastrophic bleeding while the patient waits for care.

Access barriers due to lack of familiarity with specialized coagulation services:

Initial diagnosis is often delayed for Nevadans who have suspected bleeding disorders when they do not have access to the state's federally recognized HTC. Because genetic bleeding and clotting disorders are not common, most hospitals and private practices are unfamiliar with complex laboratory diagnostics and genetic testing required to obtain an accurate diagnosis. Referrals that are required to first pass through a preferred provider network results in delays in diagnosis and treatment, increasing the risk for prolonged hospitalization until a diagnosis is determined. HTC services include expertise in diagnostic testing, resulting in rapid and accurate diagnoses required for appropriate treatment.

Cost: Despite caring for medically complex patients with a multitude of co-morbidities (including costly co-infection of Hepatitis C and HIV) care provided as early as 1984 in federally recognized treatment centers has reduced the overall costs for this population (Smith & Levin, 1984). Federally recognized hemophilia treatment centers are also better equipped to administer and appropriately dose factor and newer non-factor therapies that have experienced rapid advances in the last five years.

Solution to resolving access barriers: All health plans currently providing insurance products in Nevada should cover the services of federally recognized hemophilia treatment centers including diagnosis and patient care as well as access to discounted 340B outpatient specialty pharmacy. Federally designated hemophilia treatment centers can meet or reduce the current evaluation and management fee schedule offered to non-federally designated hematology/oncology providers and reduce the cost of care across the state while simultaneously improving quality of life, patient experience of care, and health outcomes.

Stakeholders and Impact

Insurers: Insurers, while initially hesitant to include federally recognized hemophilia treatment centers in their network due to unfamiliarity with the breadth of their services and impact, stand to realize significant savings by including these centers in preferred provider listings for hematology care. Comprehensive care delivered in an annual frequency reduces the need for frequent and costly office visits and reduces hospitalizations. Access to expert knowledge of available therapies reduces inappropriate utilization and long-term costs from unnecessary complications.

Patients and Families: Patients and families stand to gain the most from this proposal. Patients and families can expect to experience fewer hospitalizations, fewer missed days of work and school, personalized expert treatment, increased satisfaction, and improved quality of life. Patients and families will have access to research protocols accessible solely through federally recognized hemophilia treatment centers.

HTC clinicians: HTC Clinicians will be able to promptly and fully care for patients with bleeding disorders which will reduce cost and improve patient health outcomes and functioning. HTC clinicians will be able to increase patient participation in Centers for Disease Control Registry and other research initiatives which aim to improve therapeutics and the pursuit of cures. Increasing the numbers of patients enrolled in research yield more robust results which can accelerate the development of evidenced-based care.

Conclusion

Nevadans with bleeding disorders deserve access to expert care. Access to comprehensive federally recognized hemophilia treatment centers not only provides this expert service but also reduces patient/family as well as public and private costs. Nevadans treated in these centers deserve access to centers experienced in the reducing mortality and morbidity in their population while simultaneously utilizing fewer health care resources. The inclusion of these centers in health plans covering the state of Nevada is necessary to improve the lives of patients with suspected and diagnosed bleeding disorders across the state.

References

- Smith, P. S., & Levine, P. H. (1984). The benefits of comprehensive care of hemophilia: A five-year study of outcomes. *American Journal of Public Health, 74*(6), 616-617.
- Soucie, J. M., Nuss, R., Evatt, B., Abdelhak, A., Cowan, L., Hill, H., Kolakoski, M., & Wilbur, N. (2000). *Blood, 96*(2), 437-442.
- Soucie, J. M., Nuss, R., Evatt, B., Abdelhak, A., Cowan, L., Hill, H., Kolakoski, M., & Wilbur, N. (2001). *Haemophilia, 7*, 198-206.