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CHEROKEE NATION®
Health Services

Rare Disease Taskforce Report

Background

On February 29, 2024, Principal Chief Chuck Hoskin Jr. signed an executive order establishing the Rare Disease Task Force. This initiative advances awareness and tackles the unique challenges associated with rare diseases both on and off the Cherokee Nation Reservation. The Task Force's primary objectives include:

1. The Task Force should engage all relevant internal staff and external partners and experts to inform its work.
2. The Task Force should review existing services and resources that are currently available to patients and families
3. The Task Force should gather information to make further recommendations to the Principal Chief to enhance the Nation's efforts.
4. The Task Force should advice the Principal Chief as to the structure and process of a permanent "Rare Disease Advisory Group", within Health to advice Health Leadership and the Principal Chief, by further executive order.
5. The Task Force shall complete its work and issue a final report no later than January 31, 2025.

The Cherokee Nation Health Services Rare Disease Task Force plays a pivotal role in advocating for patients living with rare diseases. By thoroughly examining contemporary and historical treatment approaches, the Task Force has enhanced patient and family care while continuing to drive improvements in care systems to meet evolving needs.

Task Force Activity

Over the past year, the Rare Disease Task Force has achieved significant progress in critical areas, including a lab stewardship committee to consider specialty lab available (including genetic testing) and relevant to our patients, while following evidence based medicine. We also saw the planning phase of a research department and the development of system wide cancer care coordinator positions. Cherokee Nation Health Services is a sub-recipient of the Improving Cancer Outcomes for Native American Communities (ICON) research grant, in collaboration with the OU Stephenson Cancer Center, which focuses on lung cancer screening and navigation of patient care. It is important to recognize that some cancers are classified as rare diseases. According to the American Cancer Society, in the United States, rare cancers are defined as those with fewer than 6 cases per 100,000 people annually, accounting for approximately 20% to 25% of all cancer diagnoses. This underscores the critical need for specialized research, targeted treatment approaches, and dedicated support services to address the unique challenges faced by these patients and their families.

Lab Stewardship Committee

The development of a Lab Stewardship Committee provided a pathway for our physicians and advanced practice providers to curate a laboratory menu specific to our tribal healthcare needs. Additionally the Rare Disease Task Force ensured collaboration with legal teams to review and refine laboratory testing contract language to safeguard data sovereignty and establish safe partnerships for patients while maintaining ethical and secure testing practices.

Rare Disease Summit

The Rare Disease Task Force organized a Rare Disease Summit on November 21, 2024 at the campus of the Cherokee Nation Outpatient Health Center and Oklahoma State University College of Osteopathic Medicine at Cherokee Nation. The summit brought together medical experts, patients, caregivers, and community leaders to foster collaboration and discuss best practices in rare disease care, along with patient education on current services available within our health system. Topics covered included:

- Creutzfeldt-Jakob disease (CJD) and Neurosyphilis
- Ehlers Danlos Syndrome
- Primary Central Nervous System Vasculitis
- Pediatric Potpourri
- Rare Ocular Complications of Diabetes
- Unmasking the Unseen: Infectious Diseases as Indicators of Rare Underlying Condition

Feedback from the post-summit survey highlighted several positive aspects of the event, such as the quality of guest speakers, the panel discussion moderated by Dr. Beth Harp, the Ehlers Danlos Syndrome PowerPoint presentation, the variety of topics, opportunities to speak one-on-one with presenters, breakout sessions, and the focus on mental and physical well-being, including pediatric information. However, attendees noted areas for improvement, including inadequate notice, a lack of patient-centered focus, an overly packed schedule for one day, and the absence of some presenters in person.

Participants also suggested topics for future summits, including increased focus on pediatrics, pain management and its mental health impacts, topics related to Cherokee Nation initiatives such as STI and infection prevention, Charge Syndrome, real-life experiences with dual professional-patient tracks, advocacy presentations, continued focus on Ehlers Danlos Syndrome, prevention over treatment, and patient perspectives on conditions such as Brugada Syndrome, Long QT Syndrome, and Takotsubo Cardiomyopathy. Further exploration of CJD and Rosa Dorfman Blood Disease was also requested.

The summit successfully facilitated meaningful discussions, provided valuable insights into rare disease management, and highlighted areas for improvement and growth in future initiatives.

Rare Disease Case Management and Cancer Care Coordination

One of the most significant advancements this year is the appointment of a dedicated Registered Nurse (RN) case manager for rare disease patients. Acting as a patient navigator, this role is crucial in helping patients traverse the often complex and challenging landscape of rare disease treatment and care. The case manager works closely with both the primary care team and specialists to close any gaps in care, ensuring that all aspects of the patient's treatment are well-coordinated. In addition, they assist patients with access to critical resources, help to guide them within the tribal health system, and facilitate referrals, durable medical equipment (DME) needs, and any other services necessary for comprehensive rare disease care. As the program evolves, there will be a continual evaluation for additional personnel to ensure a personalized and detailed care management plan that addresses the unique needs of each patient. Ongoing evaluation, planning, and development will help ensure that patients receive the most effective and tailored care possible.

Cancer care, particularly pediatric cancer, often involves navigating complex and life-altering challenges, and it has become a model for how rare disease management can evolve. According to the National Cancer Institute, rare cancers account for approximately 25% of all pediatric cancers diagnosed in the United States each year. A significant step in improving cancer care has been the increased collaboration between oncology teams, primary care providers, and specialists. By fostering open communication and early intervention through an effective monitoring system, cancer care teams are now able to facilitate early referrals when cancer is even just suspected, leading to faster diagnosis and more timely treatment. This collaborative approach has also paved the way for rare disease management to follow suit, ensuring that patients with rare diseases receive similar levels of coordinated, proactive care.

Cancer care case managers play a vital role in supporting patients throughout their treatment journey. They help patients navigate the complexities of cancer care while serving as reliable sources of information for both patients and their families. These professionals provide compassionate support, explain treatment plans in detail, address concerns, and proactively seek solutions to any challenges that may arise. Their responsibilities include fostering clear communication between patients and healthcare providers, ensuring timely access to specialized care, and overseeing all aspects of the treatment process. By offering continuous support, they help ease the emotional and logistical challenges faced by patients and their loved ones, making the overall experience more manageable.

Furthermore, cancer care case managers are now available at each clinical site, providing additional critical support for patients diagnosed with cancer. They help guide patients through the complexities of their care journey, strengthen partnerships with area health systems, and ensure patients have access to the full spectrum of resources and expertise needed for their treatment. This model of care ensures that cancer patients, particularly those with pediatric diagnoses, have a cohesive, well-supported path forward—one that rare disease management teams aim to replicate as they continue to evolve and improve care for individuals with rare diseases.

Enhanced Services within Cherokee Nation Health Services

The Cherokee Nation Health Services network has expanded to provide comprehensive, in-house care for rare disease patients and those requiring complex care. New and existing services include:

- Adult and Pediatric Psychiatry
- Rehabilitation Services (inpatient and outpatient), including physical therapy, occupational therapy, and speech-language pathology

- Dental and Specialized Dental Care
- Cleft Palate Clinic
- Dedicated Pediatric and Hospitalist Teams providing 24/7 hospital support
- Patient Experience Team, led by the Chief Experience Officer focusing on improving patient satisfaction
- Ear, Nose, and Throat (ENT) and Allergy
- Adult and Pediatric Neurology
- Adult Cardiology
- Gastroenterology for Adults
- Pediatric and Adult Endocrinology
- Maternal-Fetal Medicine
- Optometry Specialty Clinics:
    - Retina Clinic
    - Ocular Disease Consult Clinic
- Electrodiagnostics Clinic

Behavioral Health Integration

Behavioral health professionals, including licensed clinical social workers and psychologists, have been integrated into select sites to provide mental health support for patients with complex conditions and their families. This holistic approach ensures both physical and mental health needs are addressed. Integrated behavioral health professionals also ensure close communication with any additional behavioral health needs for the patient or their family and can assist with facilitating any other care needed within the behavioral health department.

Inpatient Specialty Services

Inpatient care continues to offer access to specialties such as neurology, nephrology, and cardiology. Inpatient services have also continued to expand with the addition of placement of cardiac loop recorders and expanded EEG capabilities with plans to introduce transesophageal echocardiography, further improving diagnostic and treatment options for our patients.

Recommendations

The Rare Disease Task Force has identified several key initiatives to ensure the continued advancement of rare disease care and support within Cherokee Nation Health Services. These recommendations build upon the progress achieved over the past year and align with the long-term vision for comprehensive, patient-centered care.

1. Continuing the Rare Disease Summit: June 2025

Building on the success of the inaugural Rare Disease Summit, the Task Force recommends making this event an annual or biennial gathering for patients, family members and other advocates, along with healthcare providers. The next summit, proposed for June 2025, will:

- Foster collaboration between healthcare providers, patients, researchers, and community leaders.
- Highlight advancements in rare disease care and genetic research.
- Provide a platform for sharing patient stories and identifying gaps in current services.
- Foster partnerships with academic institutions, tribal health organizations, and regional healthcare systems to further innovation in rare disease management.

Regular summits will strengthen the Cherokee Nation's role as a leader in rare disease advocacy and care.

2. Establishing a Permanent Rare Disease Advisory Group

To ensure the long-term sustainability of the Task Force's work, it is recommended that a Permanent Rare Disease Advisory Group be established. This group will:

- Serve as a consultative body to the Principal Chief of the Cherokee Nation and Cherokee Nation Health Services Leadership.
- Monitor the implementation of recommendations from the Task Force's final report.
- Provide ongoing evaluation of rare disease policies, resources, and services to ensure they meet the evolving needs of patients and families.
- Facilitate communication between stakeholders, including patients, healthcare providers, and community members, to maintain a patient-centered approach.

The advisory group will consist of representatives from key stakeholder groups, including healthcare professionals, legal experts, and patient advocates to ensure comprehensive and informed guidance.

3. Expanding Behavioral Health and Specialty Services

To further support patients with rare diseases, the Task Force recommends the continued integration and expansion of behavioral health and specialty services. Specific actions include:

- Increasing the availability of licensed clinical social workers and psychologists at additional clinical sites.
- Expanding inpatient specialty care capabilities, including neurology, cardiology, and diagnostic services such as transesophageal echocardiography.
- Enhancing coordination between behavioral health professionals and case managers to provide holistic care for patients with complex medical and mental health needs.

4. Developing Financial Support Mechanisms

To address financial barriers faced by patients with rare diseases, the Task Force recommends:

- Expanding efforts to identify and secure insurance coverage for patients requiring specialized care through collaboration with our patient benefit coordinators.

- Explore the creation of a fund or financial assistance program specifically for rare disease patients, supported by grants or philanthropic partnerships.
- Collaborate with other Cherokee Nation departments for social needs and programs available within our Nation.

5. Strengthening Data Sovereignty and Research Partnerships

To ensure the protection and ethical use of patient data, the Task Force recommends:

- Continuing collaboration with legal teams to uphold data sovereignty in laboratory testing (including genetic testing) contracts.
- Continue exploring partnerships with research institutions that prioritize tribal sovereignty and patient privacy in rare disease studies, in addition to development and expansion of our own Cherokee Nation Health Research Department.

6. Continued Growth of Rare Disease Case Management

Continued evaluation of the volume of rare disease patients within the health system should occur to confirm that appropriate personnel are available to ensure a personalized and detailed care management plan that addresses the unique needs of each patient.

The rare disease case management program should continue to offer support to individuals impacted by rare disease and consider establishing a rare disease support group that is similarly structured to the CNHS cancer care support group. These support groups for patients, caregivers, and survivors build a network of community, resources, and support that extends beyond the clinical setting. This ongoing effort will help reduce the emotional and logistical burdens on patients and their families, making their care experience more manageable while improving long-term outcomes and fostering a supportive community.

By implementing these recommendations, the Cherokee Nation Health Services can continue to lead in the provision of innovative and culturally competent care for rare disease patients, ensuring we meet the needs of this vulnerable population with dignity and respect.

Conclusion

The efforts of the Rare Disease Task Force, in collaboration with Cherokee Nation Health Services, have resulted in significant advancements in the care and support provided to patients with rare diseases and their families. Through policy development, care coordination, expansion of a research department, expansion of specialized services, and community collaboration, the Task Force has laid the foundation for a sustainable and patient-centered approach to rare disease management.

Our unwavering commitment to delivering comprehensive, high-quality care ensures that rare disease patients receive the attention and resources they deserve. Moving forward, continued professional development, continued education opportunities, community events, and patient feedback will ensure the best patient experience and contribute to positive healthcare system growth.

By prioritizing innovation, collaboration, and culturally responsive care, Cherokee Nation Health Services reaffirms its leadership in rare disease advocacy and its dedication to improving the health and well-being of all citizens.

The establishment of the Rare Disease Task Force by Principal Chief Chuck Hoskin Jr. on February 29, 2024, has set the stage for groundbreaking advancements in rare disease care and advocacy within Cherokee Nation. With its primary objectives focusing on enhancing awareness, reviewing existing services, and making recommendations for improvements, the Task Force has already made significant strides in improving the lives of patients with rare diseases. Through the development of new resources like a dedicated case manager for rare disease patients and collaborations with medical experts and health systems, Cherokee Nation Health Services is leading the way in addressing the complex challenges these patients face.

Over the past year, the Task Force has achieved key milestones, including organizing the first Rare Disease Summit, launching a lab stewardship committee, and expanding services within Cherokee Nation Health Services which includes the addition of a rare disease case manager and system wide cancer care case managers. These initiatives have fostered collaboration among healthcare workers, patients, and the community, providing a solid foundation for continued progress. Looking ahead, the Task Force is committed to further enhancing care by implementing new recommendations, such as establishing a permanent Rare Disease Advisory Group, expanding behavioral health services and developing financial support mechanisms for patients. The integration of case management models from cancer care, particularly pediatric cancer, is another critical step in ensuring comprehensive, coordinated care for individuals with rare diseases.

The ongoing growth of rare disease case management, supported by dedicated professionals who navigate the complexities of care, will be pivotal in ensuring patients receive tailored, effective treatment. As the program evolves, there will be an increased focus on collaboration, education, and community support, including plans to introduce support groups and explore philanthropic opportunities for rare disease patients, much like those in cancer care.

With these continued efforts, Cherokee Nation Health Services is poised to not only meet the needs of rare disease patients but also to lead in innovative, culturally competent care for this vulnerable population. The Rare Disease Task Force's work, alongside the dedication of Cherokee Nation Health Services, affirms the commitment to improving the health and well-being of all citizens, ensuring that rare disease patients receive the comprehensive care, resources, and support they deserve. Through these initiatives, the Cherokee Nation remains at the forefront of rare disease advocacy, delivering quality, patient-centered care with dignity and respect.

Respectfully,

January Hoskin

First Lady January Hoskin

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