

Telegenetics and Access to Specialty Care in Wyoming

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Wyoming Telehealth Network ECHO Presentation ~ October 30, 2019

Learning Objectives

Upon completion of this presentation, participants will be able to:

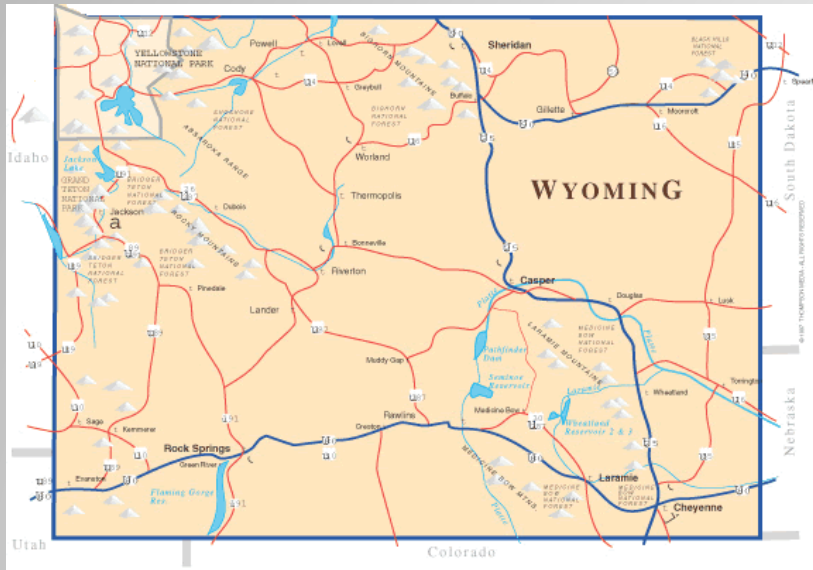


- Describe the current structure of genetic services in the State of Wyoming.
- Understand the barriers and challenges of providing, and accessing genetic services in Wyoming.
- Describe the three phases of the Wyoming Telegenetic Program Evaluation.
- Summarize evaluation results and identify at least one quality improvement opportunity.

Previous Wyoming Genetic Clinic Structure

- From its inception until 2012, the clinics were staffed by practitioners from the Denver Children's Hospital
- Beginning in 2012 to current, the University of Utah has the contract
- Approximately 208 patients were seen on an annual basis via in person genetic clinics
- In person clinics were held at local public health nursing offices in: Cheyenne, Casper, Sheridan, Gillette, Jackson, Rock Springs and Riverton

Implementing Telegenetics in Wyoming



- Large geographical area with no practicing geneticists
- Questions regarding cost and need for services in Wyoming
- No formal evaluation tool to assess the program and who it benefits

Telegenetic Needs in Wyoming

- Access to genetic services is extremely limited in rural communities
- Rural Health efforts to make telehealth more widespread by equipping PHN offices with webcams
- Due to the dynamic field of genetics, patients are often seen for follow-up appointments to aid in proper diagnosis and treatment plans
- Recognized as a tool for service delivery in underserved communities
- Geneticists work in urban areas, primarily, through large health systems and academic health science centers



Where are we now?

- We are currently into our second year of piloting an in-person and telegenetic hybrid model
- Clinics are held in Cheyenne, Casper and Riverton
- Return patients are seen via telegenetics, while new patients are scheduled for in-person clinics



Evaluation Questions

1. Who are we currently serving?
2. What would happen if there were no Wyoming genetic clinics?
3. Is telemedicine an acceptable option for patients and providers?

Phase I

- Intake Survey
- Client Survey

March 2018 (on-going)

Phase II

Nurse & Front-line
Staff Focus Group
(Qualitative)

October
2018

Phase III

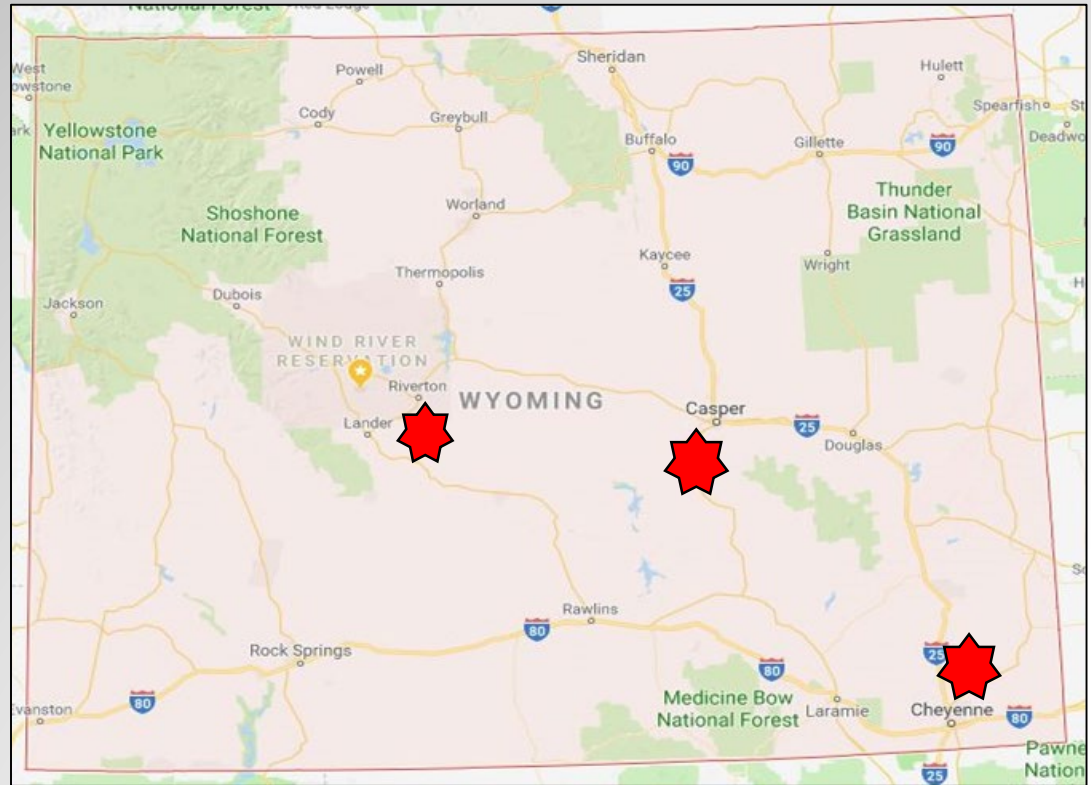
Consulting Provider
Expert Interviews
(Qualitative)

December
2018

Evaluation Phase 1: (Quantitative)

★ Telegenetic Clinics:

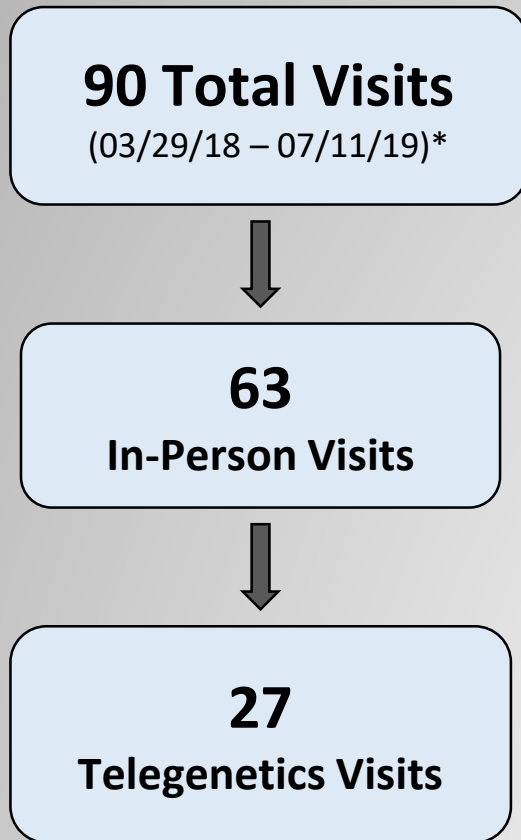
- Casper
- Cheyenne
- Riverton



Phase 1 Data Collection Includes Two Surveys:

- 1) **Intake Survey** – Carleigh interviews families during the program enrollment process.
- 2) **Client Survey** – Families use an iPad after their visit (in person or telehealth) to complete a Google Form with more questions about their visit experience.

Evaluation Phase I



Initial Visit: *In-person*



Next Visit: *Telegenetic*

What data are we collecting?

- Name, Address
- Visit Type/Location
- Health Insurance Type
- Severity of Condition
- Race/Ethnicity
- Education Level
- Total Household Income
- Burden & Barriers to Care
 - Distance/Time Traveled
 - Childcare Needs
 - Access to genetic service
 - Other options for genetic services
- Telemedicine Acceptability
- Telemedicine Satisfaction

*One Telegenetic clinic was held in September (Casper, September 26th, 2019); these survey results are not included in totals.

Who were we serving? (n=90)

Patient

- **Gender:** 63% male, 31% female, 6% missing
- **Age:** 0 to 46 years; average age 10 years
- **Insurance Provider:** 56% WY Medicaid, 30% Private



Adult Patient or Patient Family/Caregiver

- **Education:** High School/GED or less than High School (67%)
- **Medically Underserved Area Resident?:** Yes (58%)
- **Income:** \$ 20,000 or less annually (34%); \$ 20,001 to \$ 40,000 (22%)
\$ 40,001 to \$ 60,000 (13%); \$ 60,001 and higher (21%)

(Visits from 03/29/18 – 09/16/19)

What would happen if there were no more Wyoming clinics? (n=90)

If there were no Wyoming genetic clinics (check all that apply)

- 53% - Travel to another clinic (Denver, SLC, Billings, “another city”, “anywhere”)
- 50% - Wait 6 months or more
- 34% - Would not have gotten services
- 36% - Said “I don’t know.”

78% had not tried to get genetic services somewhere else.

Of those that had sought services elsewhere, they traveled most often to Denver and Salt Lake City.

One respondent said the wait for Denver Children’s was over 18 months.

Is Telehealth An Acceptable Option? (n=27*)

- 89% felt that telegenetics made it easier for them/their child to receive services
- 85% said it was the first time they had used telemedicine
- 89% agreed that telemedicine was more convenient than traveling
- All (100%) were satisfied with the quality of services they received
- All (100%) said that all of their questions were answered.
- 44% said that they would have preferred an in-person visit with the specialist even if it meant traveling.

Patient/Family Comments

- *Transportation is a issue for our family.*
- *We would not have been able to travel to Denver to get this done.*
 - *It was a great clinic. It was nice not to have to travel.*
- *Very happy could get an appointment much sooner at the Wyoming office.*
 - *I am very thankful that this program is available.*

* Responses only from patients/families who had a telegenetic service.

Evaluation Phase II & III (Qualitative)



We started with the literature:

Taylor J, Coates E., Brewster L, Mountain G, Wessels B, Hawley MS. (2014). Examining the use of telehealth in community nursing: identifying the factors affecting frontline staff acceptance and telehealth adoption. *Journal of Advanced Nursing*. 71(2), 326-337.

Dr. Taylor was kind enough to share her expert interview questions with us.

Focus Group Process

Date (2018)	Place	Staff Roles	Qualitative Interview Type
October 18	Laramie/Cheyenne Health Dept.	2 nurses, 1 front-desk/clerical	Focus Group
October 30	Natrona/Casper Health Dept.	2 nurses, 1 front-desk/clerical	Focus Group
December 11	University of Utah	Consulting Provider	Expert Interview

Our Questions:

1. How well does telehealth fit into your role?
2. Were you supported in using telehealth?
3. How easy or difficult has it been to use telehealth with patients?
4. What are the pros and cons of using telehealth for the Wyoming Genetic Clinics?
5. Do you have any thoughts on ways to improve the technology or how it is used in the program?

Results: Assets and Challenges

Assets

- Families appreciate the shorter travel times and more time spent with the doctors.
- University of Utah medical team is very well liked by both nurses and families.
- Knowledge gained is benefiting beyond patients/families.
- Some families already use telehealth for diabetes and mental health counseling.
- Staff are happy that telehealth equipment is now being used (purchased 10 years ago).

Challenges

- Transportation continues to be an issue – particularly for Natrona County where the nearest bus stop is 6 blocks from health department.
- Some staff would like more Zoom training (in-person training).
- Spanish materials are needed. Two additional languages that would be helpful were Chinese and French.
- In Cheyenne, FE Warren AF Base will continue to be a steady supply of families.

Results: Assets and Challenges

Clinical Issues

- Laramie County site know most of the patients attending while Natrona County staff do NOT.
- Paperwork for Natrona families is generally not in the same county. This can lead to delays and missing information.
- When patients are referred back to their county for services, they need a resource person familiar with their region.

Relationships

- The overall family experience is positive.
- I-Pad data entry (client survey) has been challenging for some.
- Families need to understand what a telehealth visit is – and having a visual may help.
- They also need repetition. Hearing how telehealth visits are unique may clarify questions.
- Texting is the preferred method to remind families.
- A “road-show” to talk about telehealth may be helpful to referring clinics.

Results: Program Improvement

- Consider adding another site in Fremont County?. **(We did!)**
- Market the program to local providers. **(We are!)**
- A local genetic resource specialist is needed in the patient's home county. **(Working on this...)**
- Both Cheyenne and Casper could use supplies and equipment to support their clinics. **(Progress here too!)**



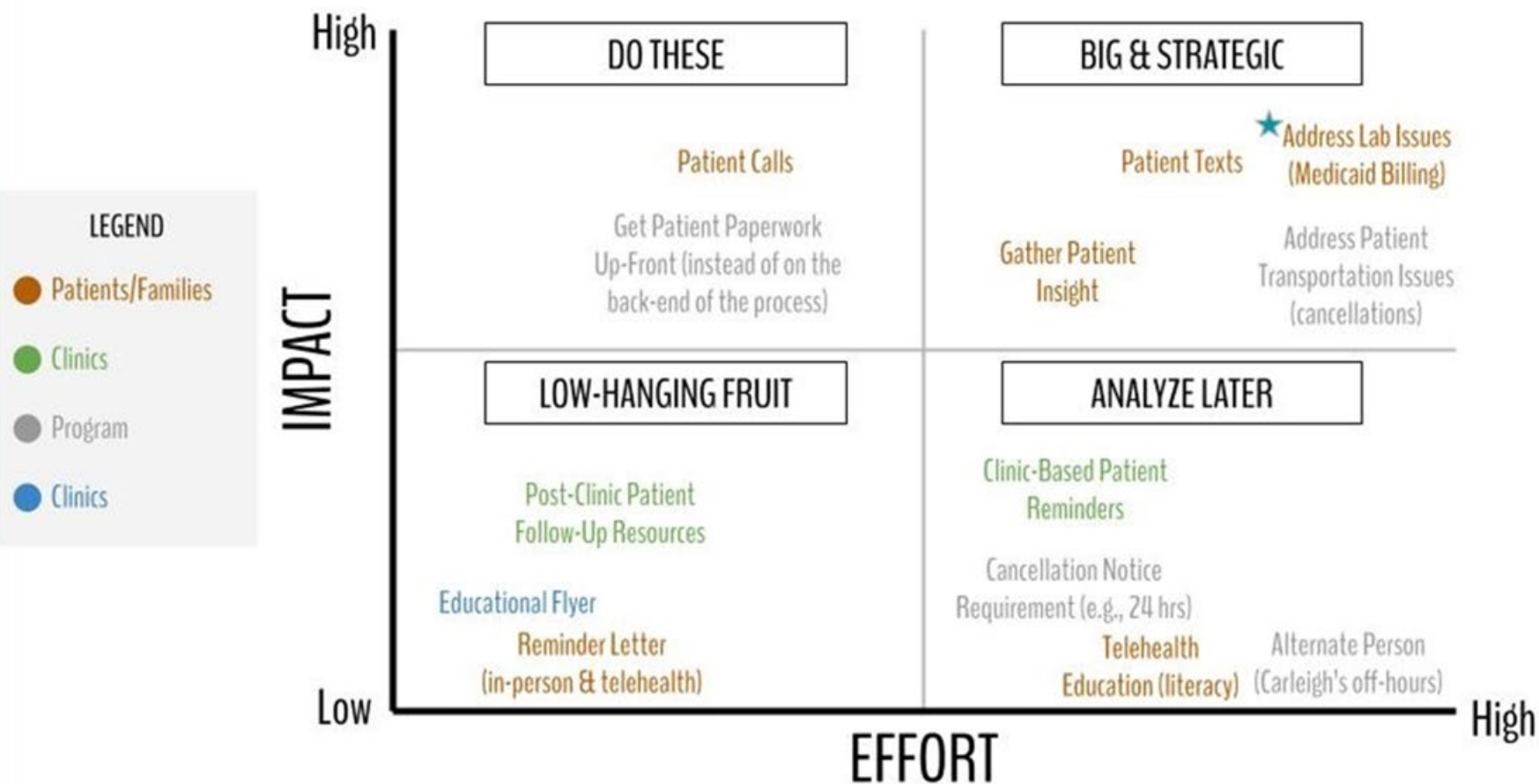
Evaluation: Final Thoughts



- Mixed method (quantitative and qualitative) provided more information than either would alone.
- The Wyoming Telegenetic program **IS** reaching the people that we hoped to reach (primarily lower income, in need of services).
- Nursing and clerical staff were very pleased to be *asked* their thoughts.
- There are no clear-cut answers. But we learned more about the problem and received some valuable insights from the front-line professionals.

Next Steps

Genetics Clinic Impact/Effort Plot



The Future

1. Improve Referral Process
2. Improve Patient Reminders for all clinics
3. Resource Map for current clinics
4. Expand the number of Genetic clinics
5. Continue partnership with Public Health Nursing staff in local county health offices.

Wyoming Genetics Clinic Schedule 2019

Bringing Genetics Services to Families
Across Wyoming



2019 In-Person Genetics Clinic Dates & Locations

Casper	Cheyenne	Riverton
Thursday, July 11	Wednesday, July 10	Thursday, June 13
Thursday, October 17	Friday, October 18	Friday, June 14

2019 Telegenetics Clinic Dates & Locations

Casper	Cheyenne	Riverton
Thursday, June 6	Thursday, June 20	Tuesday, October 22
Thursday, September 26	Thursday, November 14	

The Wyoming Genetics Clinic Program is coordinated by the Wyoming Department of Health with clinical services provided by the University of Utah Division of Medical Genetics. Insurance is only billed if testing is recommended and pursued. Funding for the Wyoming Genetics Clinic Program is provided by the Title V Maternal and Child Health Services Block Grant Program, Health Resources & Services Administration.

For more information on accessing genetics services in Wyoming, please contact the Newborn Screening & Genetics Coordinator at 1-307-777-6297 or call our toll-free number: 1-800-438-5795



Nicola Longo MD, PhD is a professor of Pediatrics, an adjunct professor of Pathology at the University of Utah School of Medicine, and chief of the Division of Medical Genetics. He is an expert in inherited metabolic diseases and is intimately involved in the treatment of patients with these diseases at Primary Children's Medical Center. His basic and clinic research covers disorders of fatty

acid oxidation and carnitine metabolism and the development of novel treatments for metabolic disorders including phenylketonuria, organic acidemias, and lysosomal storage disorders.



David Viskochil MD, PhD is a professor of Pediatrics and one of the clinical geneticists in the Division of Medical Genetics. He serves as co-Director of the NF Clinic at the University of Utah and is the Director of Clinical Genetics Services in the Division of Medical Genetics. His research has focused on the molecular genetics of the neurofibromatosis type 1 (NF1) gene, and bone health and cancer malignancy in patients with NF1. He has published over 50 research and clinical reports and serves on study sections for the Department of Defense and NIH.

Mississippi Example

University of Mississippi Medical Center
Department of Pediatrics, Medical Genetics
2500 North State Street
Jackson, Mississippi 39216
P | 601.934.1900
F | 601.984.1916



March 26, 2019

Patient Name
Address
City, State Zip

We have scheduled a Telehealth Genetics appointment for **Patient Name**. Please call our office at 601-984-1900, Option 2, if you are unable to attend this appointment.

Friday, April 19, 2019 at 10:45 am
At Children's of Mississippi Tupelo Clinic in Tupelo, MS

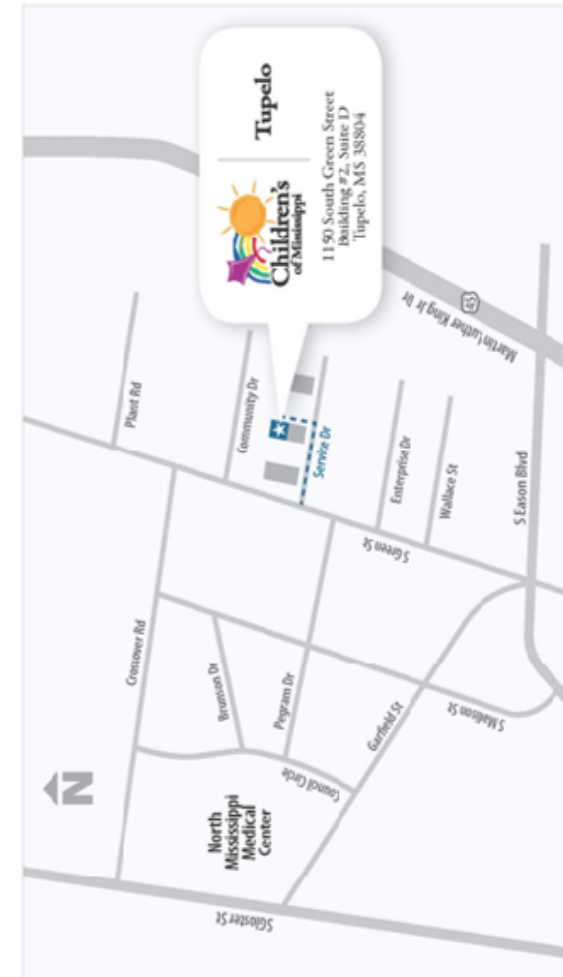
In order to better meet the needs of our patient population here in Mississippi, we are now offering genetics services by interactive video. This process is referred to as "telemedicine" or "telehealth." This means you will be evaluated and treated by a health care provider or specialist from Jackson, MS while you are physically located in Tupelo, MS.

At the end of the visit, we ask that you please take a few moments to complete a survey about your experience. This will help us evaluate and improve our services. We thank you in advance for your help with this brief survey.

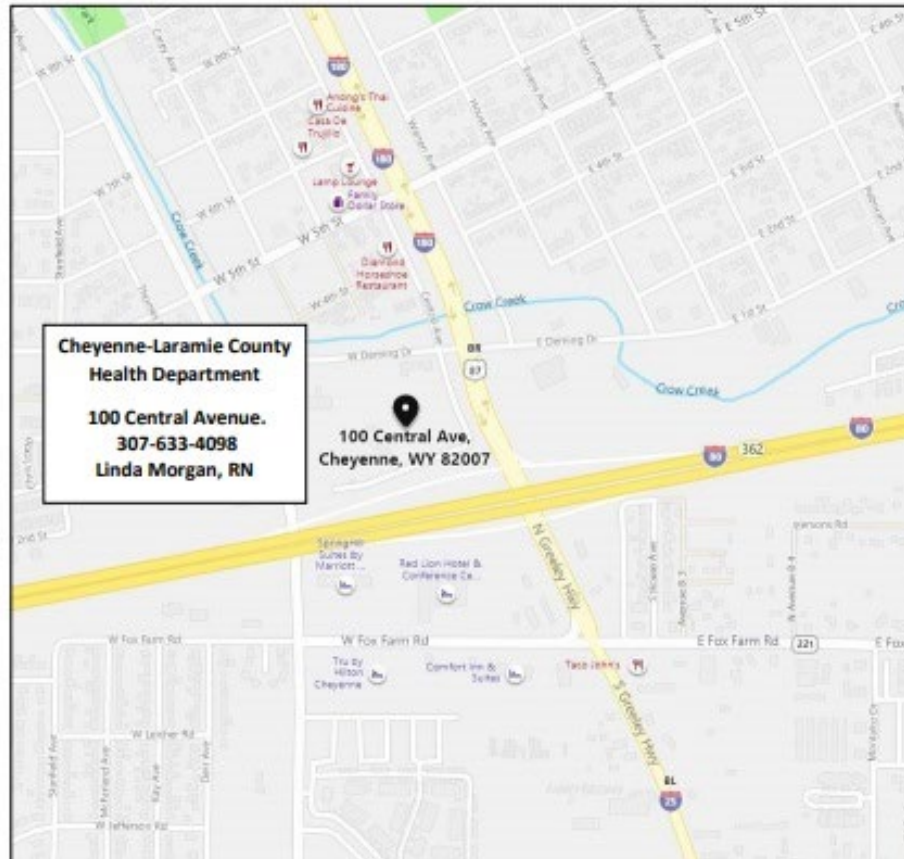
Your entire visit with us is expected to last approximately 1 hour. We ask that you arrive 15 minutes early for your appointment to allow time for registration. It is very important that you keep this [appointment](#) as rescheduling could significantly delay this evaluation.

Please note that this Genetics clinic is NOT located on UMMC's main campus or at NMMC. Please refer to the map on the back of this letter for specific directions. The address for the Children's of Mississippi Tupelo Clinic is 1190 South Green Street, Building #2, Suite D, [Tupelo, MS 38804](#). If you have any trouble finding the clinic on the appointment day, please call the clinic's front desk at 601-825-2575.

Please do not hesitate to call our office with any questions. You can reach our genetics office at 601-984-1900, option 2.



Wyoming Genetics Clinic Host Site ~ Laramie County Health Department, Cheyenne, Wyoming



The **Wyoming Genetics Clinics** are coordinated by the **Wyoming Department of Health** but are hosted at a number of sites around the state.

Your appointment will be at the **Cheyenne-Laramie County Health Department** which is located on the south side of Cheyenne, near the intersection of I-80 and S. Greeley Highway. If you have problems finding our building, call the Health Department staff at 307-633-4098.

It is **very important** that you keep this appointment as rescheduling could significantly delay this evaluation which, in turn, **delays our ability to connect you to important resources**. A limited number of visits are available at each clinic site, so please make every effort to keep this appointment with the University of Utah Medical Genetics team.

Thank you!

Contact information:

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