Heartland Tele-Medicine Update

Heartlands Large Assembly 2015

Clinical Geneticists (MD's) United States

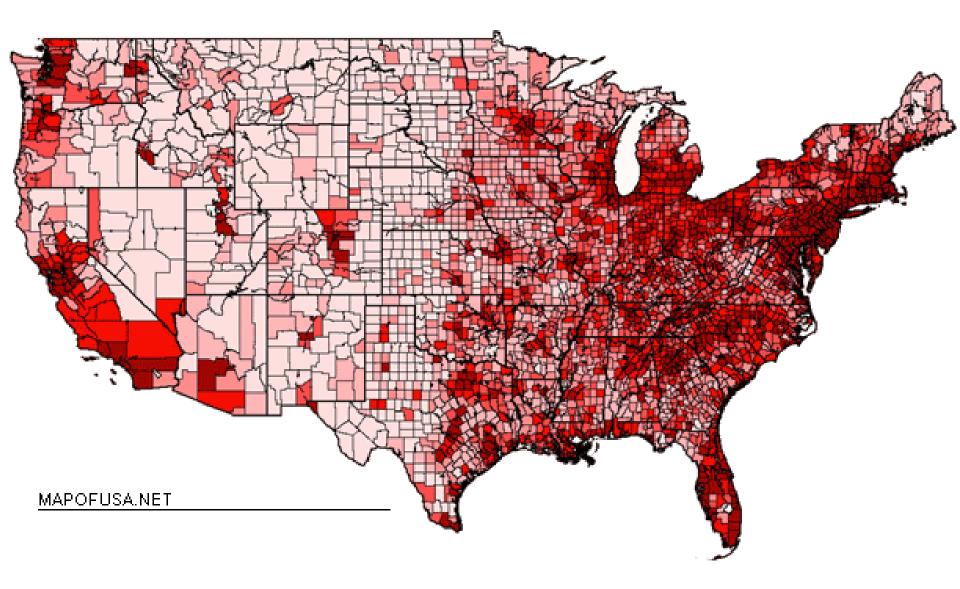
- ~ 1000 clinical geneticists
- Average 0.5 FTE seeing patients
- 1/300,000 Americans
 - **3.5 / million**
- Ratio of geneticist to children
 - **1:5,748,082**
- 0.15% of all MD physicians
- 16 trainees for all US 2010

Workforce Study

- Global deficiency in health care providers in clinical genetics
- Most critical shortage for metabolic geneticists
- Current training output is at a rate that is not even close to keeping up with the turnover rate

Demography of the Central US

- Large expanses of land
- Small populations
 - Frontier' counties
- Limited number of primary care providers, let alone specialty providers



THINGS THAT CAN BE DONE BY TELEMEDICINE

With current technology, any activity that you can do in person can be accomplished as a tele-genetics service

B. Schaefer

Challenges

- 7 deadly words of program development
- Techno-phobia
- Administrative inertia
- Cost
- Lack of adequate IT infrastructure
- Lack of colleague buy in
- Where to go for answers

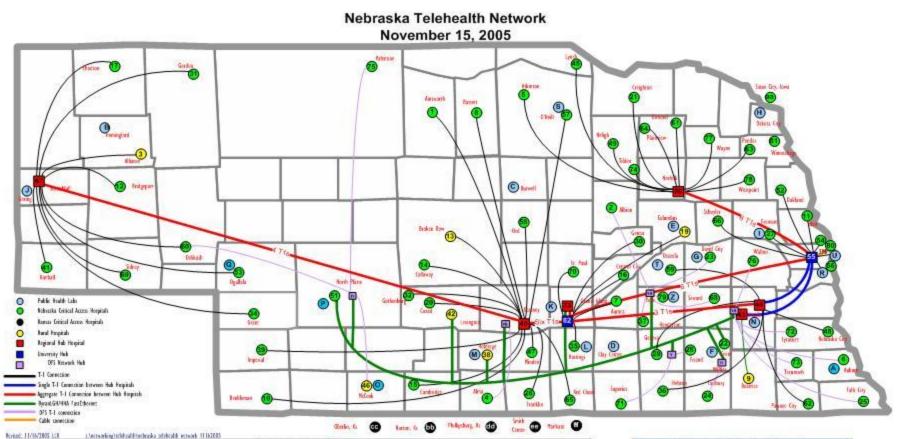
Dysmorphology

- Completely feasible
- Technology dependent
- Training of on-site personnel
- Our own `case-control studies' showed nothing missed

Statewide Telehealth Services for Children with SHCN

- 3) Discipline specific consultative services on difficult cases (available for all MMI disciplines listed above)
- 4) Continuing education / training. An ongoing series of special topics, issues in the care of CSHCN, and new updates would be provided. These activities would be open to a broader audience than those for direct patient services.
- 5) Quality assurance monitoring of local teams. This would include help with Federal compliance reviews, ongoing team monitoring, and technical assistance in the development of local QA activities.
- 6) Provision of quaternary interdisciplinary services only available in Nebraska metropolitan areas

Speciality services in complicated disorders may only be found in Omaha and sometimes Lincoln. Even if the primary discipline is available to the patient, complex cases may require quaternary services. Examples of such services would include the interdisciplinary teams as well as services in sleep disorders, eneuresis / encopresis, autism and the neurobehavioral team.



Nebraska Hospitals							N
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dd. Philipsburg, Ks

ee. Smith Center, Ks ff, Mankato, Ke

Phillips County Hospital Smith County Memorial

Jewell County Hospital

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Transition Consultation

- Interdisciplinary team
 - Consumer / Family Advocate
 - Nurse
 - Adult psychiatrist (dual diagnosis)
 - Pharmacist
 - Developmental Pediatrician
 - Med-Ped physician
 - Ancillary (Genetics, Dentistry)

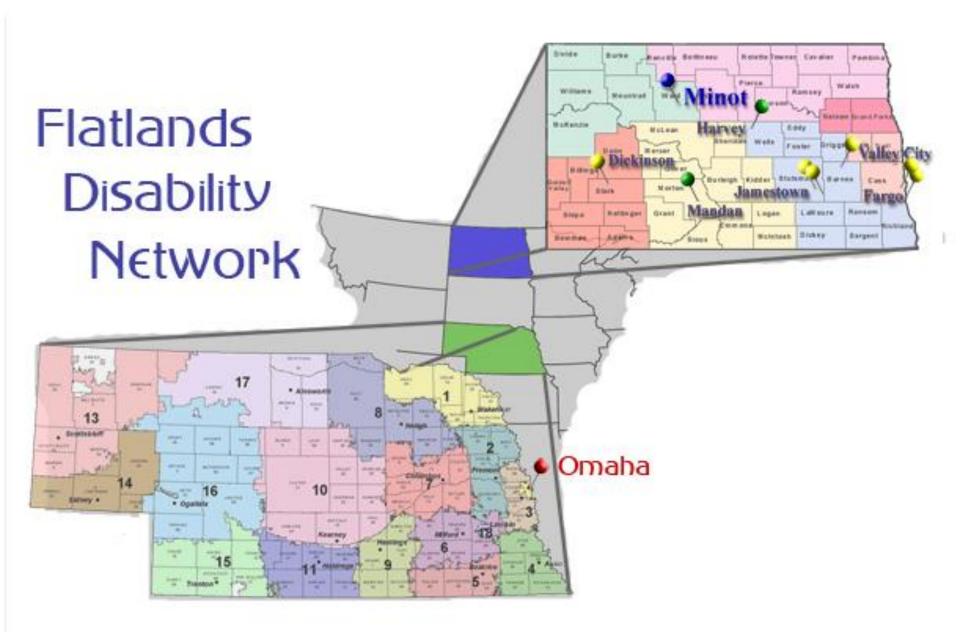
Flatlands Disability Network



Flatlands Disability Network - Activities



The Flatlands Disability Network provides a mechanism to provide training, therapy services, supervision, and coordination in the delivery of services to people with disabilities. Specific services such as speech / language therapy, wellness training, nutrition counseling, and behavioral health monitoring are delivered over the FDN. More comprehensive descriptions of the services provided over FDN will be provided here as they become available.



Shriner's Cooperative Agreement

USE AGREEMENT

THIS USE AGREEMENT entered into as of this _____ day of _____, 2006, by and between Munroe Meyer Institute ("MMI") and Shriner's Hospital for Children – Twin Cities ("SH").

WHEREAS, the parties are affiliated in providing pediatric health services and education, and

WHEREAS, SH desires to provide telemedicine health services ("Services") to its patients utilizing for this purpose ("Usage Purpose") Telehealth equipped facilities ("Premises") at MMI located at Annex 8 Building, 412 Saddle Creek Road, Omaha Nebraska,

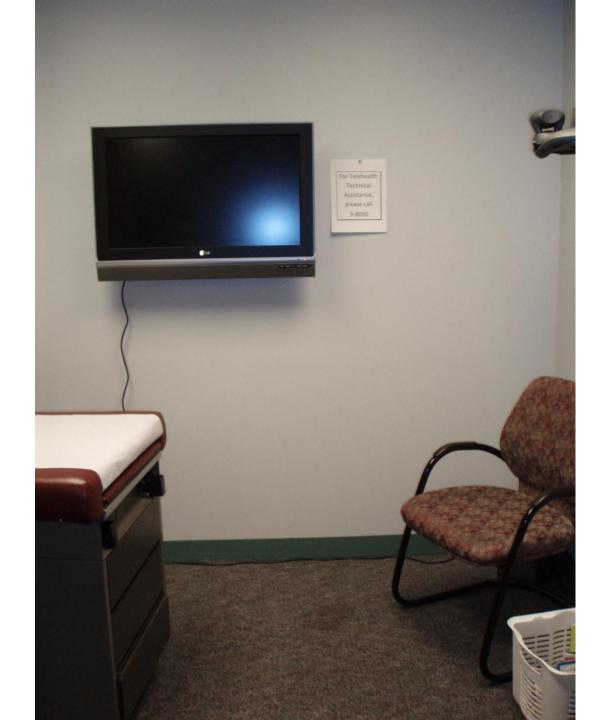
WHEREAS, MMI desires to make such space available to SH to use for such purpose, and

WHEREAS, each party represents and warrants that it has the right to enter into this USE AGREEMENT (hereinafter "AGREEMENT"), upon the terms and conditions hereinafter set forth;

NOW THEREFORE, in consideration of the premises and mutual covenants herein contained, the parties hereto agree as follows:

1. TERM

This AGREEMENT, as it applies to SH's right to use the Premises, shall be for a term of one (1) year from the date of this AGREEMENT and renewable for one year periods by mutual consent of the parties.



THINGS WE ARE DOING IN TELE-GENETICS IN THE HEARTLAND



1. Genetic Emergencies

- Consultation and recommendations to outlying NICU's and nurseries
 - Triage
 - Management
 - Diagnoses

Telehealth Unit Mapping 5.27.10

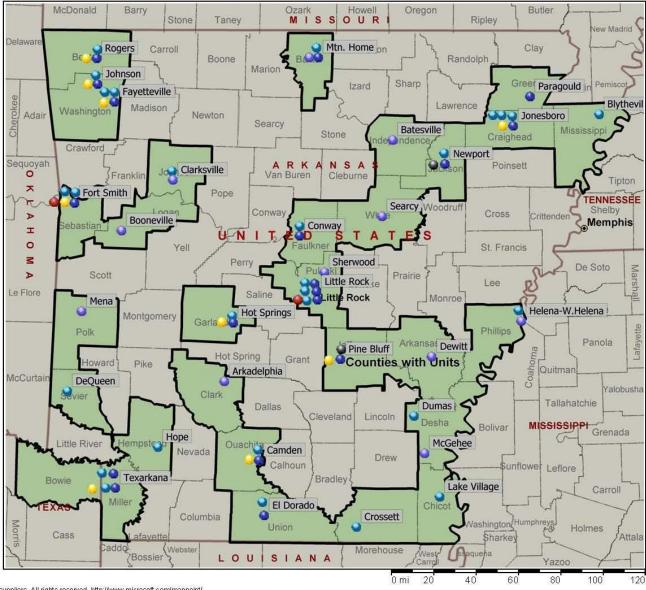
Pushpins



- Tele-nursery
- ARSAVES-Spoke sites
- ARSAVES-Hub sites
- ANGELS-NBS
- ANGELS

Custom territories

Counties with Units



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Additional NICU support

- Wichita
- Tulsa
- Overland Park, KS

2. Outreach Clinics

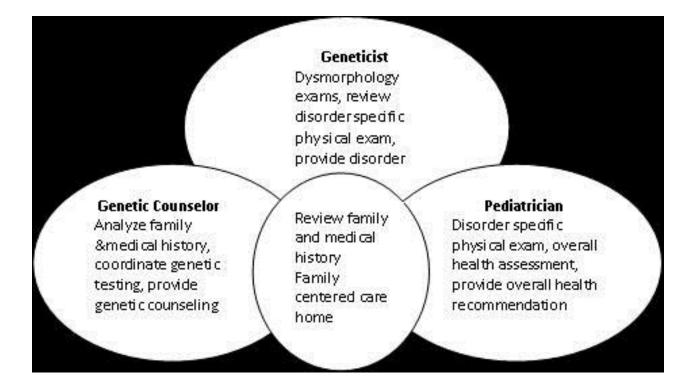
Outreach Clinics

Wichita

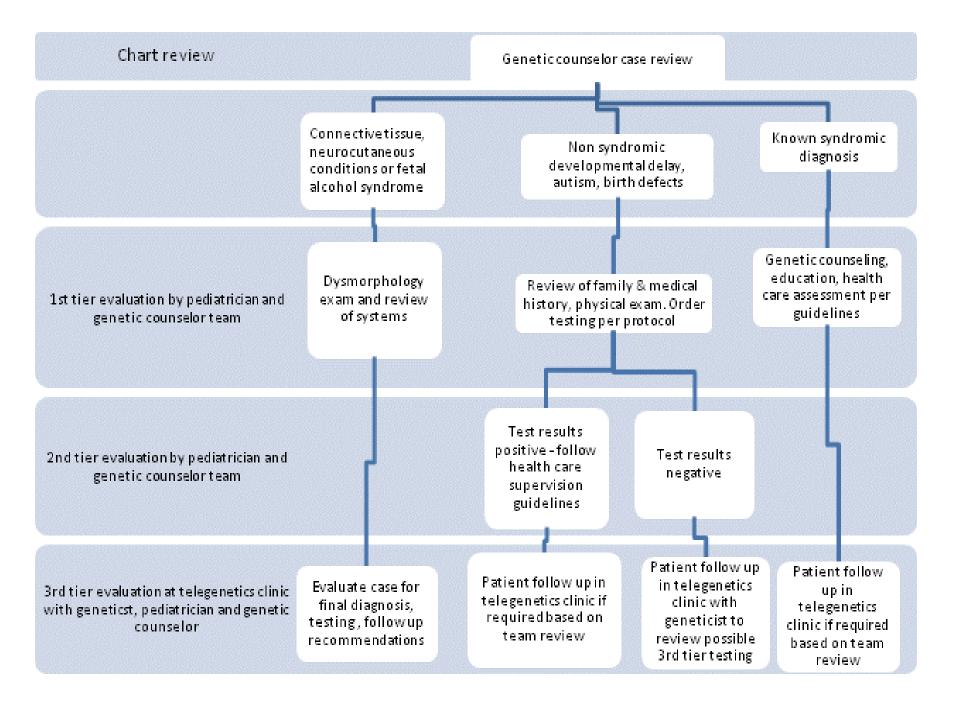
- 1 genetic counselor
- UAMS physician support (telemed)
- Pediatric physician



Overlapping Roles in Telegenetics Clinic



Adapted from Williamson, L., LeBlanc, D. (2008)



3. Ongoing Therapies

- Metabolic disorders particularly good fit
- Case management
- Triage

4.Diagnostic Dilemmas

National Birth Defects Center

Teleconference

June 17, 2008 May 6, 2008 April 2, 2008 March 5, 2008 **December 19,2007** October 30, 2007 September 18, 2007 July 18, 2007 June 12, 2007 May 22, 2007 April 17, 2007 March 20, 2007 February 28, 2007 **December 19, 2006** November 28, 2006 October 17, 2006

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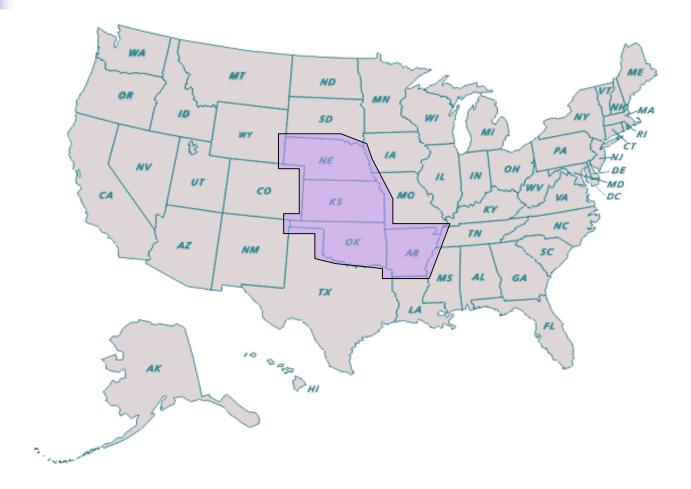
Am J Dis Child, Vol. 147, Issue 11, 1196 November 1, 1993

ARTICLES

Telediagnostic conferencing

M. Feingold; J. Frias; A. E. Lin; G. B. Schaefer; M. Horwitz

5. Mid-America Genetics Education Consortium



TELEMEDICINE MANUAL FOR CLINICAL GENETIC SERVICES

A 'How To' Guide to Getting Started

Heartland Regional Genetics and Newborn Screening Collaborative: Clinical Services Workgroup

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Editors

Lori Williamson (OK) Robin Troxell (MO) Shona Whitehead (OK) John Mulvihill (OK)

Schaefer GB, Butler B, Nale D. Telemedicine manual for clinical genetic services: Heartland Genetics and Newborn Screening Collaborative. May be accessed at http://www.heartlandcollaborative.org for electronic download. HRSA Grant U22MC03962: 2010.