

A Novel Approach in Telegenetic Services Pediatrician and Genetic Counselor Team

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FOR MEDICAL SCIENCES



**SHOBANA KUBENDRAN
SIDDHARTHAN SIVAMURTHY
BRADLEY SCHAEFER**



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Current Genetic Service Delivery Model

Outpatient Telegenetics Clinic

KU SCHOOL OF MEDICINE
WICHITA
The University of Kansas



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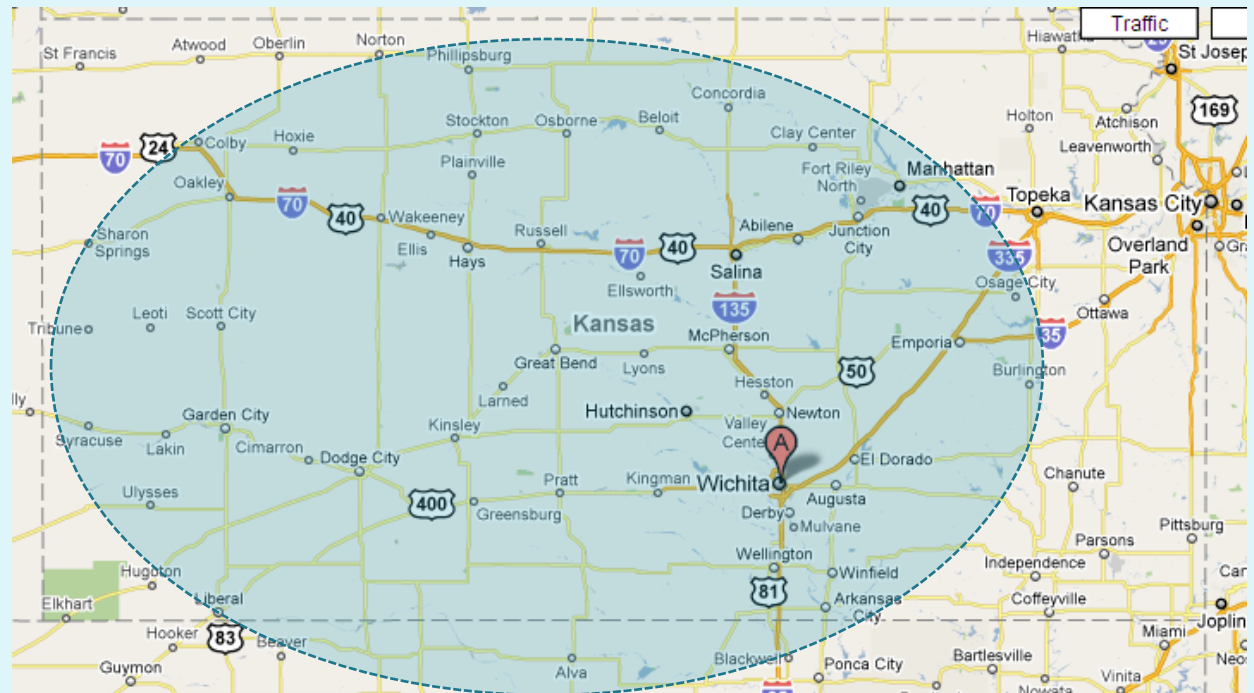


Held every other Monday 9:00 to 11:00
~ 4 patients per clinic day
142 patients evaluated to date
Waitlist 4 months – and increasing

Telegenetics Clinic Referral Base



- 50% Wichita or within 100 miles
- 50% 1.5 to 3 hours away
 - Pratt
 - Liberal
 - Dodge City
 - Garden City
 - Hays



Challenges



- National average 3.5 geneticists/million population
- Kansas <2 geneticists/million population
- Increasing wait for appointment in telegenetics clinic

Proposal



- Expand genetic services by adding a pediatrician to the telegenetics practice model.
- Pediatrician + genetic counselor will evaluate common genetic conditions per protocol developed with geneticist
- Geneticist will supervise and support pediatrician + genetic counselor diagnostic team
- Geneticist will focus on more complicated cases in telegenetics clinic

Chart review

Genetic counselor case review

Connective tissue, neurocutaneous conditions or fetal alcohol syndrome

Non syndromic developmental delay, autism, birth defects

Known syndromic diagnosis

1st tier evaluation by pediatrician and genetic counselor team

Dysmorphology exam and review of systems

Review of family & medical history, physical exam. Order testing per protocol

Genetic counseling, education, health care assessment per guidelines

2nd tier evaluation by pediatrician and genetic counselor team

Test results positive - follow health care supervision guidelines

Test results negative

3rd tier evaluation at telegenetics clinic with geneticist, pediatrician and genetic counselor

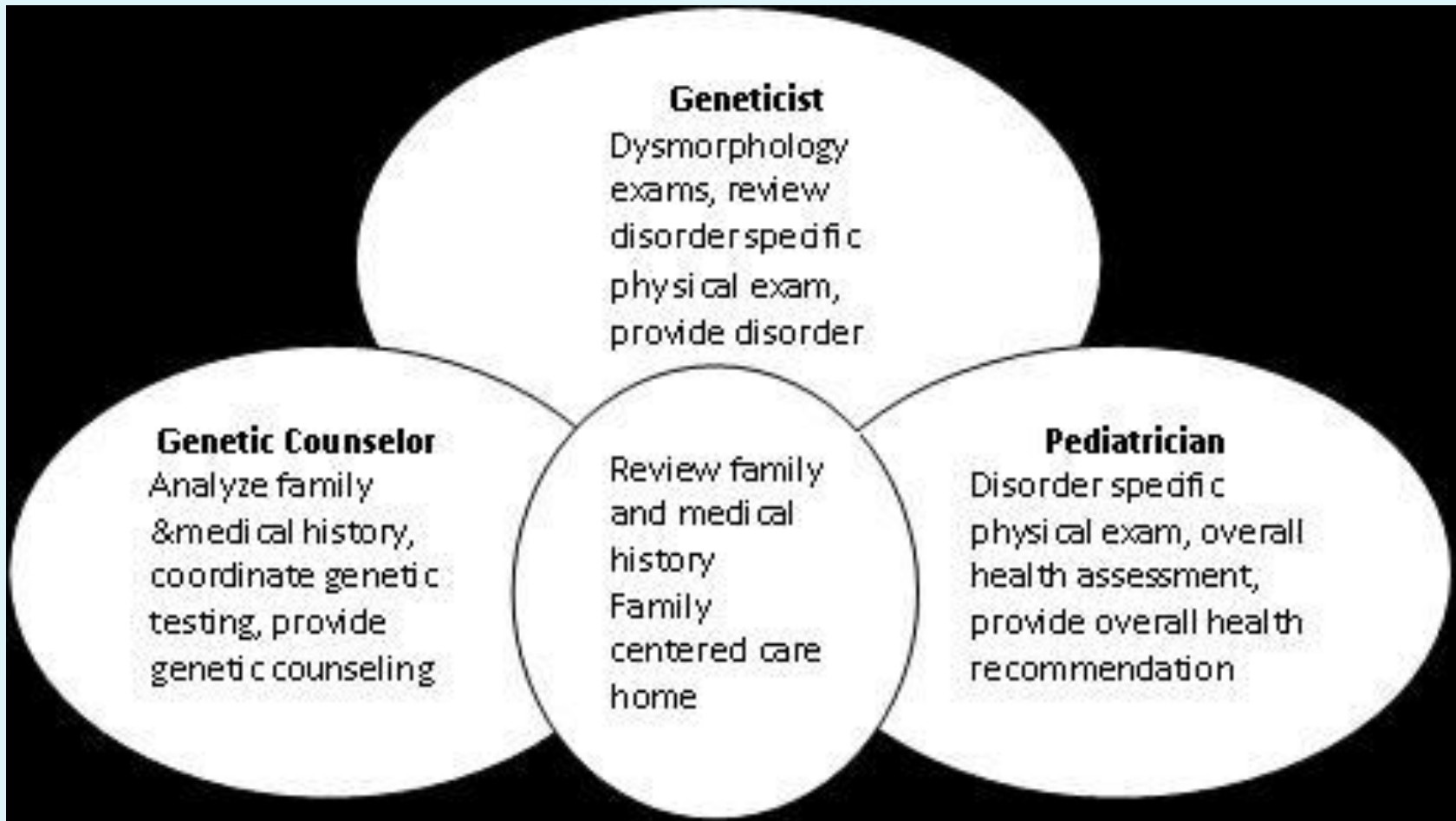
Evaluate case for final diagnosis, testing, follow up recommendations

Patient follow up in telegenetics clinic if required based on team review

Patient follow up in telegenetics clinic with geneticist to review possible 3rd tier testing

Patient follow up in telegenetics clinic if required based on team review

Overlapping Roles in Telegenetics Clinic



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

Aim



- Increase access to genetic services
- Determine if pediatrician and genetic counselor model can be sustained in current funding environment
- Assess efficacy, efficiency and patient satisfaction with this model of telegenetics delivery

Current Status



- Dr.Sivamurthy and Shobana Kubendran visited UAMS July 5th to 8th
 - Observed cases with Dr.Schaefer in genetics clinic
 - Developed draft of protocols
 - ✦ Growth abnormalities, failure to thrive, developmental delay, neurocutaneous conditions, fractures, hearing loss, low tone, fetal alcohol syndrome and connective tissue disorders
- Received IRB approval August 8th,2011
- Data collection started on August 9th
- Will insert pic of our visit to genetics clinic in Little Rock

Proposed Timeline



- **Aug 2011 – May 2011**
 - Patient and provider satisfaction survey
 - Collect billing and reimbursement data
 - Develop and publish protocols for pediatrician+genetic counselor evaluation



- Come back next year to hear success and challenges with this project !
- Thank you !