



UAMS
UNIVERSITY OF ARKANSAS
FOR MEDICAL SCIENCES

**The Three Musketeers
Of Telegenetics**




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**SUPPORTED IN PART BY A GRANT
FROM HRSA U22MC03962**

Pediatrician



Aim



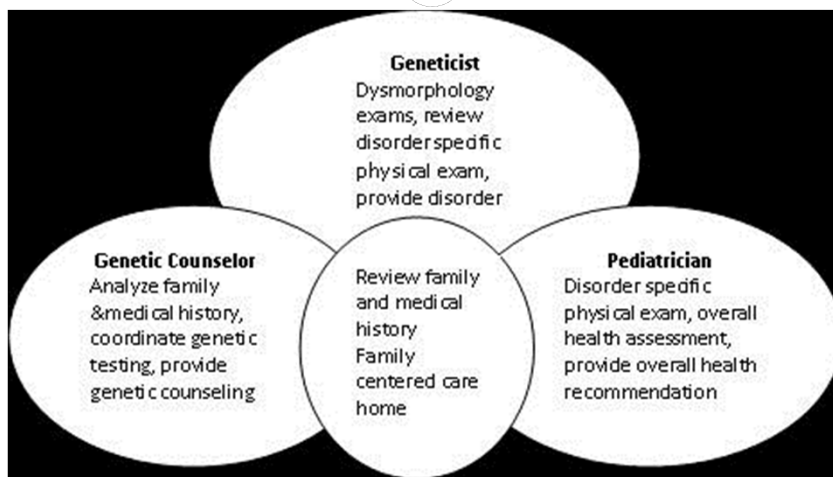
- Increase access to genetic services
- Determine if pediatrician and genetic counselor model can be sustained in current funding environment
- Assess efficacy, efficiency and patient satisfaction with this model of telegenetics delivery

Challenges

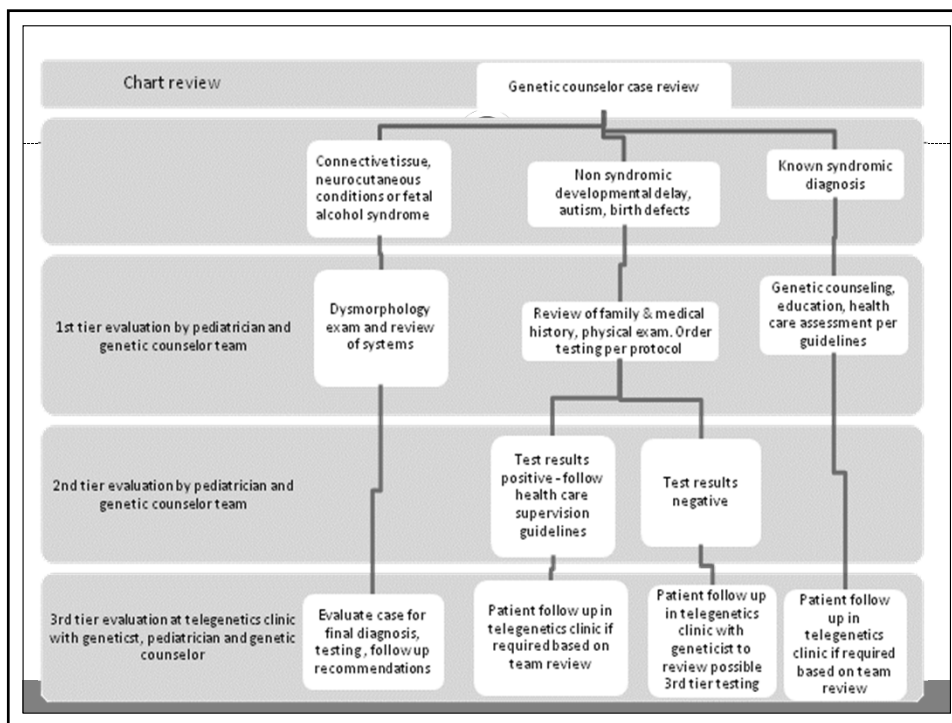


- National average 3.5 geneticists/million population
- Kansas <1 geneticists/million population

Overlapping Roles in Telegenetics Clinic



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



Project timeline

- Dr.Sivamurthy and Shobana 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
 - 8/9/11 to 8/30/12



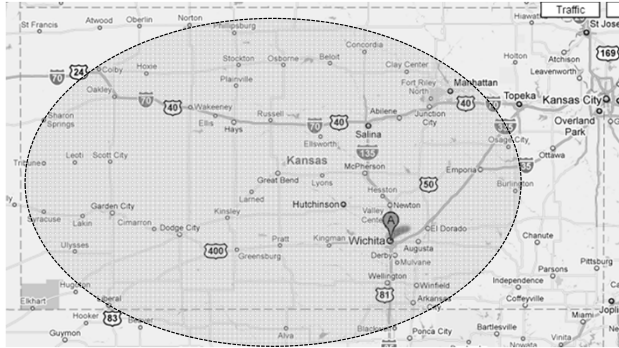
Patient Summary

- 178 patient visits scheduled
- 15 no show
 - 9 no show Schaefer appnt
 - ✦ 5 new patient
 - ✦ 4 follow up appointments
 - 6 no show Sivamurthy appnt
- 163 patient encounters
- 163 patient encounters
- 138 patients
 - 79 – Schaefer
 - 37 – Sivamurthy
 - 22 – Schaefer/Sivamurthy

Interim data summary : data collection not complete

Telegenetics Clinic Referral Base

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



Previous Telegenetics Clinic



Current Genetic Service Delivery Model Outpatient Telegenetics Clinic

KU SCHOOL OF MEDICINE
WICHITA
The University of Kansas



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Schaefer Patients

- 79 patients
- Syndromic conditions
- Referral from Dev Peds/ pediatricians/ neurologists
 - 2nd tier evaluation
 - ✦ Autism
 - ✦ Developmental delay

Sivamurthy Patients

- **37 patients**
 - 30 Developmental delay, autism, dysmorphic facial features
 - 1 Neurofibromatosis
 - 1 abnormal microarray
 - 5 inappropriate referrals

- **First tier testing**
 - Microarray
 - Fragile X
 - 15 methylation
 - MECP2

Schaefer/Sivamurthy Patients

- **22 patients**
 - 8 evaluations for Marfan syndrome
 - ✦ 7 FBN1 testing ordered
 - ✦ 2 variant of unknown significance

 - 3 patients no further evaluation
 - 3 patients – 2nd tier testing - pending
 - 6 patients – 2nd tier testing – negative
 - 1 patient – 2nd tier testing – positive

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

Results - Increase Access to Genetic Services



- Schaefer pt's 8/9/10 to 8/8/11: **75**
- Schaefer pt's 8/9/11 to 8/30/12 : **79**

- Additional **59** pt's seen 8/9/11 to 8/30/12
 - 37 – Sivamurthy solo
 - 22 – Schaefer with Sivamurthy

Interim data summary : data collection not complete

Results - Increase Access to Genetic Services



- **Decreased wait time**
 - For first tier evaluation with Pediatrician/GC
 - Wait time for second tier evaluation with Schaefer 2 to 6 months (depending on severity of case)

Results - Sustainability



- **Clinic with Dr.Sivamurthy continues once a month**
- **Billing viability – under evaluation**
- **Insurance coverage**

Results – Patient Satisfaction with Telegenetics

- | | |
|---|---|
| <ul style="list-style-type: none"> • Before today's visit, what made it hard to get the specialty services your child needs? • The information I received <u>before the visit</u> helped me understand what was going to happen. • The equipment worked well. • The use of technology did not get in the way with being able to have a good conversation with the specialist. • Despite the obstacles to receiving care in person, I would STILL prefer to travel to see the specialist. • If you had not been able to use telemedicine to get specialty care today, what would you have done? | <ul style="list-style-type: none"> • 56 patients • >90% patients <ul style="list-style-type: none"> ○ Highly satisfied • >50% would prefer telemedicine than face to face • More convenient/less gas • I really like the telemedicine, it is really nice not having to travel • I hope the other specialist begin to appreciate this technology. We live in great times! • Awesome love the people here • Thank you for providing us with wonderful care that is so easily accessible |
|---|---|

Results – Patient Satisfaction with Pediatrician/GC

- | |
|--|
| 1. The information I received <u>before the visit</u> helped me understand what was going to happen. |
| 3. Before we started, each person introduced themselves and described their role. |
| 5. The pediatrician and genetic counselor listened and respected the information I provided. |
| 6. The pediatrician and genetic counselor responded to all of my questions. |
| 7. Privacy of information about my child and my family was protected. |
| 8. I feel confident in the quality of the care provided today. |
| 9. I feel confident in the recommendations from today's visit. |
| 10. I would recommend the genetics clinic to other families. |
| 11. Overall, I was satisfied with the visit today. |

- >90% score of 5
- **Yes, even though we didn't have genetic doctor here I got the information we needed**
- **I feel very confident in the pediatrician and counselor to handle my child's case**

Lessons Learned



- Feasible concept – steep learning curve
 - “Comfort level” increased but need continued exposure
- Pediatrician a resource in pediatric clinic
- Genetic counselor a resource for PCP in community
- Dysmorphism in the eye of beholder
- Replicable – but many variables
- Referrals from family physicians
- Telegenetics suitable for scheduled clinic
- No acute PICU follow up

Lessons Learned



- Collect each piece of information upfront
- Difficult to retrieve data from EMR
 - Differentiate patient encounters
 - × (appointments vs lab visit vs location vs inpatient vs outpatient)
 - Time between referral intake and appointment time
 - Time taken to get from appointment to insurance approval
 - List of genetic tests ordered
 - Referring physician

Benefits of Telemedicine



- What does he really look like ? 😊
- Can't smell diapers!
- Acceptable method of evaluating children who do not like to be touched or make eye contact – autism

Next Step



- Complete data analysis
- Interview with referring physicians
- Publish protocols

Acknowledgements



- Angelica Alvarez – MA with Genetics Clinic
- Dr. Barry Bloom – Chair Dept of Pediatrics, KUSM
- Wesley Medical Center

Video examining

