

It Takes Two to Telemed

September 24, 2010
Des Moines, Iowa
Heartland Genetics Collaborative Conference



Experiences in Interstate Telegenetics

- History
- Funding
- Infrastructure
- Telegenetics clinic data
- Quotable quotes
- Memorable pictures
- Challenges
- Success
- Future directions

Once upon a long time ago in Wichita

- Well actually 8 years ago...
- Kansas University School of Medicine Wichita
- Dr.Cho
- Dr.Lutz
- Two genetic counselors

Coincidentally...I had to move Wichita in 2009



To boldly go where no one has gone before



- Well ...no one went for 8 years ...



Tele-genetics Idea !



<http://blog.radvision.com/images/2008/20080925-VideoOverEnterprise-Telemedicine-VC.jpg>

Supported in part by a grant from HRSA/Maternal and Child Health Bureau (Genetic Services Branch) U22MCO3962, Heritable Disorders Heartland Collaborative, through the University of Oklahoma Health Sciences Center



Participants in Interstate Telegenetics Clinic

- **University of Arkansas for Medical Sciences**
 - Department of Pediatrics
- **UAMS Center for Distance Health**
 - provide telemedicine connection expertise and support
 - telemedicine connection from WMC to UAMS
- **Kansas University School of Medicine Wichita**
 - Dept of Pediatrics
- **Wesley Medical Center**
 - clinic space, telemedicine connectivity, maintenance and support

KU Wichita Pediatrics Telegenetic Clinic



- Wesley Medical Center
- Outpatient genetic evaluation
- Inpatient consults (mobile teleded cart)
- Comprehensive genetic evaluation and management will be provided for a variety of indications such as
 - developmental delay, autism spectrum conditions
 - birth defects and dysmorphology examination
 - heritable conditions including familial cancers
 - newborn screening follow up

Wichita Side of Telegenetics Clinic



Arkansas Side of Telegenetics Clinic

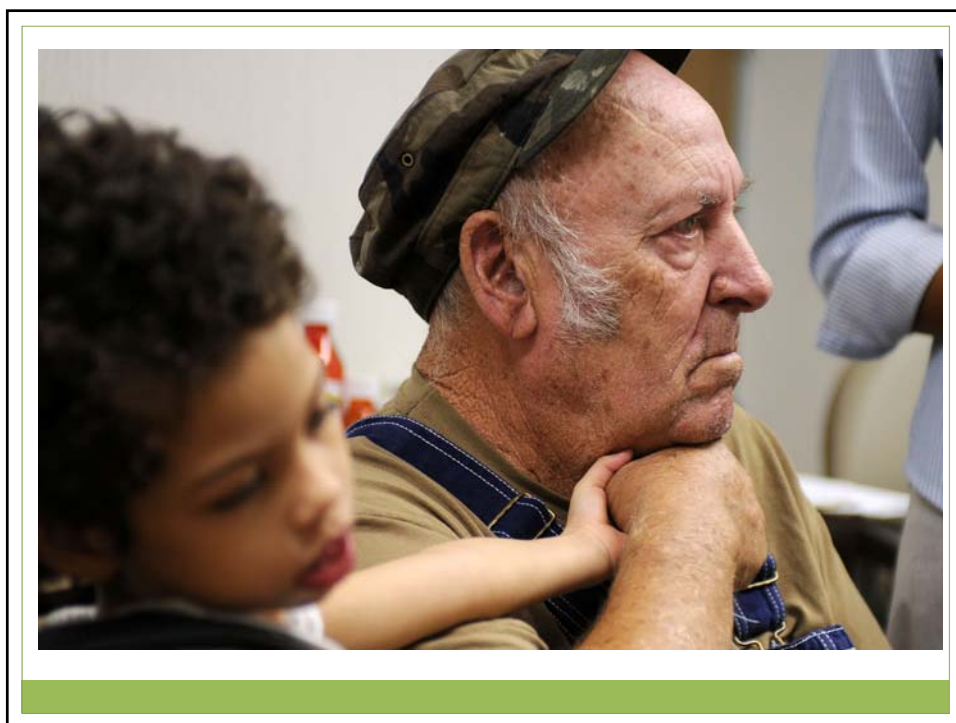


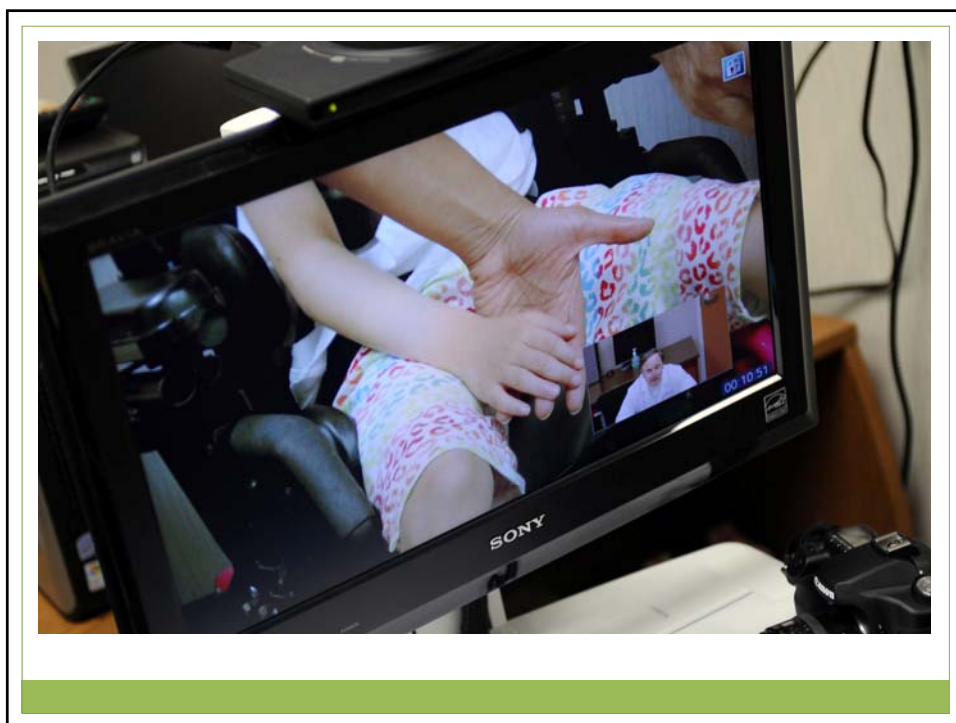
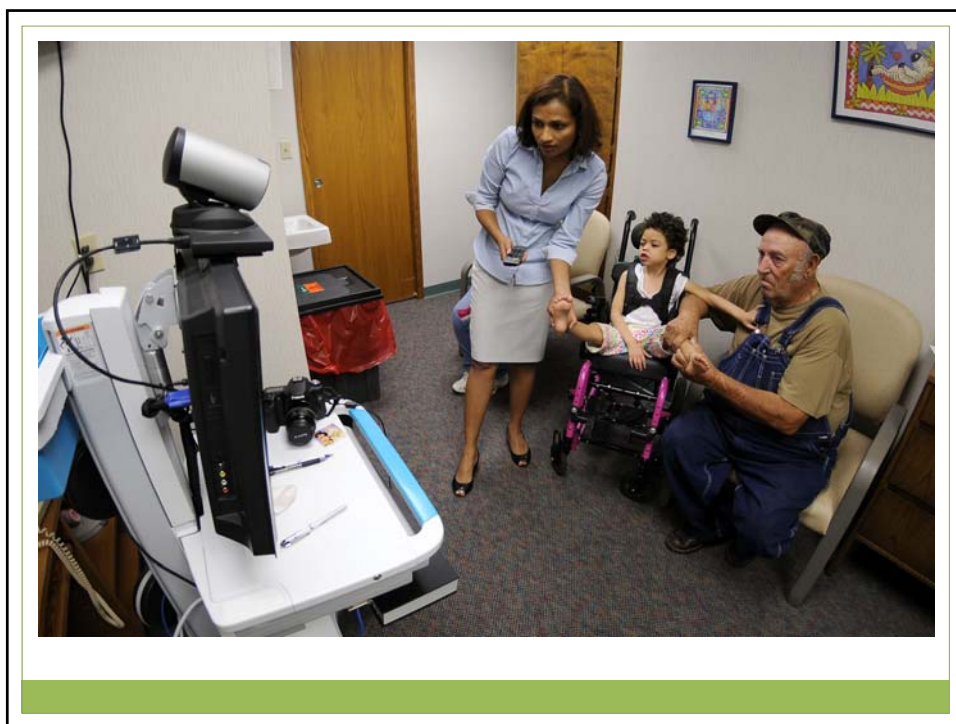
Residents evaluating case

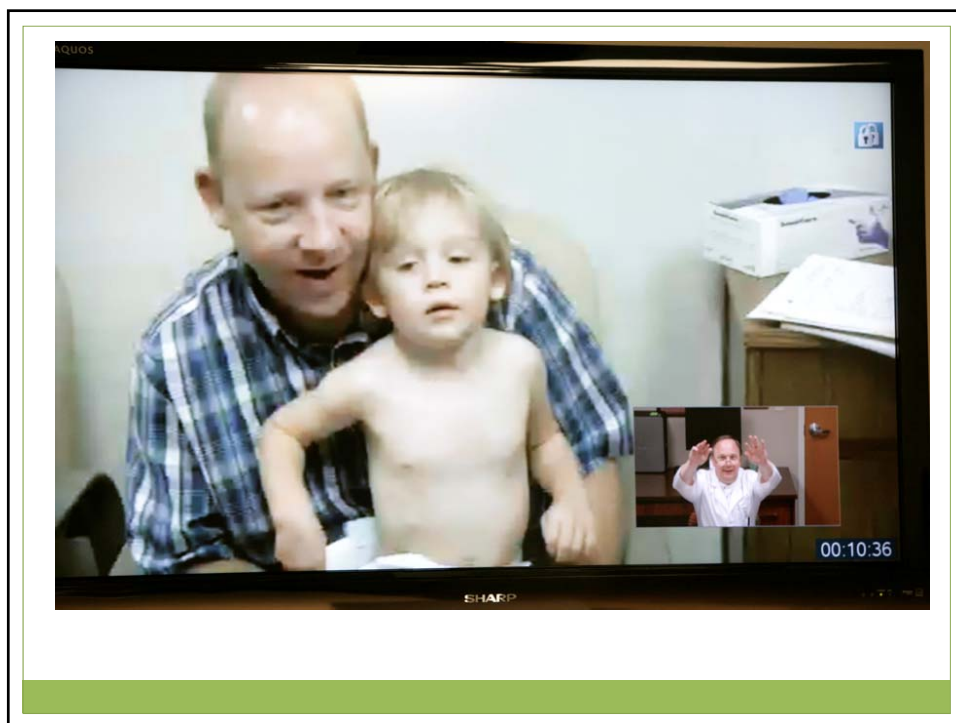
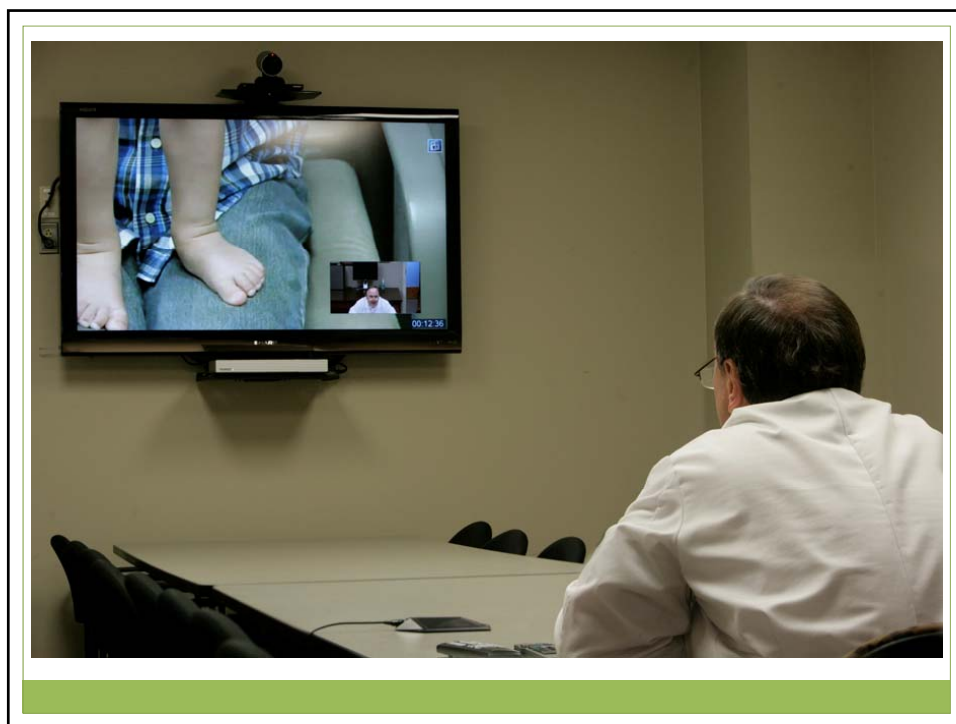


Reviewing case with family picture in picture format











Evaluation Marfan Syndrome



Quotable Quotes

- “We’ve only done this once, but we’re already happy with the benefits. For us, it’s a big plus that we don’t have to travel to reach a well known geneticist. They’re getting the exact same care without making us drive hundreds of miles, which can be tough financially.”



Children interacting with interviewer

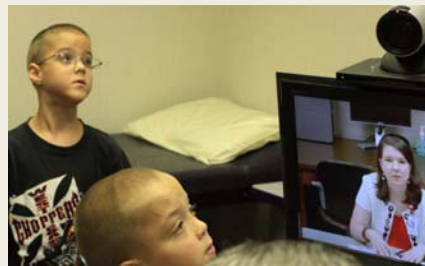


Trying to see who is behind the screen



Quotable Quotes

- “The boys are fascinated by the camera. I think most kids would be. It seems like their attention to it gives the doctor a better look at them, a better way to evaluate. It’s true that the doctor can’t reach out and touch them, but it’s still beneficial. The overall picture they get is just as clear.”



Summarize case, genetic testing and follow up with family



Timeline for Telegenetics Clinic

Month/Year	What happened
Aug 2009	Applied for grant from Heartland to fund equipment
Sept 2009	Started working at KUSM
Oct 2009	Started paperwork on Schaefer license <u>and credentialing</u>
Nov 2009	KUSM purchases one teleded unit for outpatient clinic
Jan 2010	Received grant from Heartland !
Jan 27 th , 2010	Schaefer receives KS medical license

Timeline for Telegenetics Clinic

Month	What happened
Feb 2010	Schaefer credentialing complete
March 2010	Schaefer liability insurance certificate for Kansas
April/May	Schaefer registered with insurance/ billing procedures
May 19 th 2010	Telegenetics clinic scheduled but connection suddenly stopped working ! IP address conflict and many unexpected IT problems
June 2 nd 2010	First telegenetics clinic !
July 2010	Mobile teleded cart purchased with Heartland grant installed in Wesley Medical Center NICU
Sept 2010	To date 38 patients evaluated at outpatient telegenetics clinic No inpatient consult as yet

Inpatient Telegenetics Consult

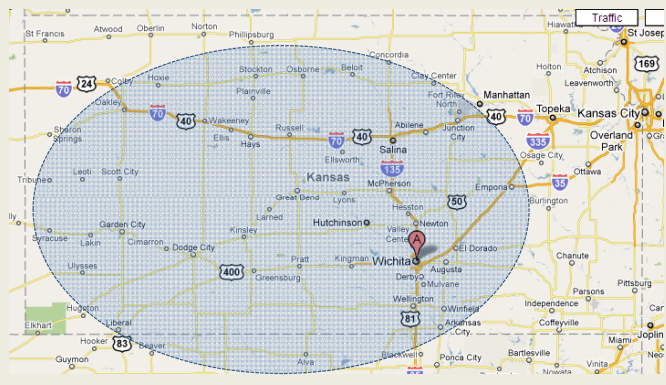
- Mobile teleded cart purchased with Heartland grant installed in Wesley Medical Center **NICU**
- 1st inpatient consult request comes from the peds floor !
 - Not adequate bandwidth on peds floor
 - Patient discharged and seen in outpatient clinic before going home
- Peds floor and Peds NICU in the process of getting wired

Outpatient Telegenetics Clinic

- Clinic held every other Wednesday 8:00 to 10:00
- 4 patients per clinic day
- 38 patients
- Pediatric
 - 5 Marfan
 - Autism, dev delay, OI, seizures, microcephaly, NF, dysmorphic features
- 4 adult
 - Marfan
 - Prenatal
- (Newborn Screening Follow up with Dr.Dasouki)

Telegenetics Clinic Referral Base

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



Telegenetics Conference



Telegenetics Education

- **Genetics Case Conference every Tuesday at 2:30**
 - Discussion of cases seen in clinic
- **Genetics education**
 - Connect through Garden City with 12 other locations
 - Updates on genetic testing
- **Equipment used by other specialties for giving lectures to distant sites**
 - Trauma care
 - Gastroenterology

Success

- Overcome barriers to access for underserved populations
- Save time and money
- Expand services
- Unexpected advantages
- Have a lot fun

This is just the beginning.....



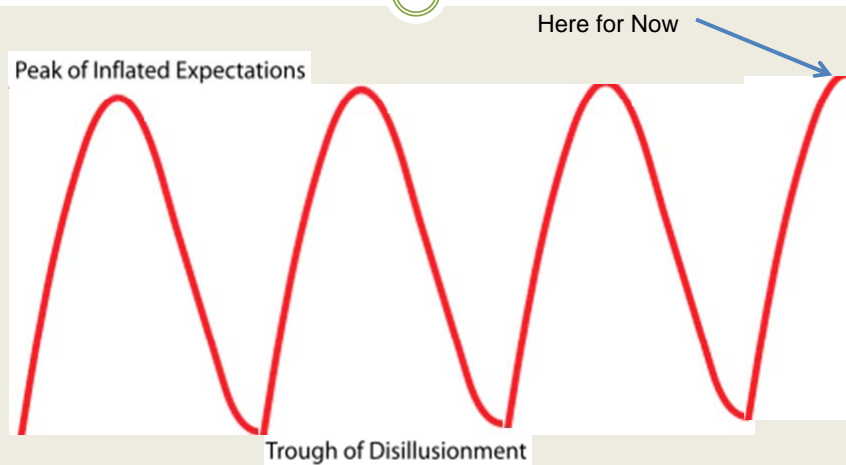
- Reimbursement
 - Consultation
 - Genetic testing
- Develop outreach clinics
- Work toward building capacity to hire geneticist and genetic counselors
- Genetics education outreach

Lessons Learned - Hype Cycle !



<http://www.gartner.com/pages/story.php.id.8795.s.8.jsp>

My Curve



Challenges

- **Techno-phobia**
- **Administrative inertia**
- **Cost**
- **Lack of adequate IT infrastructure**
- **Lack of colleague buy in**
- **Where to go for answers**
- **Rules, regulations and bureaucracy**
 - Don't try to understand it. Don't try to reason. Just do it.

Bradley Schaefer
Shobana Kubendran

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- Becky Butler
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- Stephen Kahler
- Anirudh Saronwala

Starfish Story



<http://www.tcwh.org/newmission.htm>