



## *Small Grant Update*

*Delivering genetic services to remote communities using telemedicine and web-based technologies: pilot study targeting cystic fibrosis heterozygotes*

*Marci Sontag, PhD  
and Matt Taylor, MD, PhD*



**The Children's Hospital  
Denver. CO**



*Affiliated with*  
**University of Colorado Health Sciences Center**

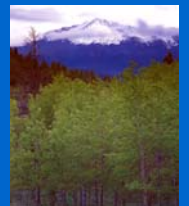
# Overall Goals and Objectives

- **To assess the current variability** in experiences with receiving genetic information for cystic fibrosis heterozygote testing
- **To establish a quarterly web-cast and telemedicine session** for couples identified as CF heterozygotes



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# Progress

- **Website developed**
  - [www.cfcarrriers.org](http://www.cfcarrriers.org)
- **Surveys developed (SurveyMonkey.com)**
  - Providers (OB/GYNs, Nurses, Family practice physicians)
  - Women who are pregnant, recently pregnant, or trying to get pregnant
- **Postcards sent with information of overall project and invitation to participate and complete survey**
  - Almost 1000 postcards sent to OB/GYNs
  - Almost 3000 postcards sent to members of Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)
  - 5000 postcards provided To OB/GYNs to provide to patients
- **Email sent to Nurse Midwives list-serve in region**




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## Pulmonary Medicine

### Cystic Fibrosis Genetic Testing

Cystic fibrosis (CF) is a life-long illness that is usually diagnosed in the first few years of life, and in many states it is diagnosed by newborn screening (including Colorado). The disorder causes problems with breathing and digestion. Cystic fibrosis does not affect intelligence. Cystic fibrosis genetic testing is being offered to couples either prior to conception or during early pregnancy. Many individuals receiving testing may have unanswered questions about their carrier status and future reproductive decisions.

**Join us for an informal discussion about cystic fibrosis and what it means to be a carrier.**  
To help answer questions regarding cystic fibrosis and cystic fibrosis genetics, we are hosting a quarterly web-cast and video conference to discuss cystic fibrosis (CF) genetics. Genetics professionals, and the cystic fibrosis care team at the University of Colorado at Denver and Health Sciences Center and The Children's Hospital in Denver are working together to give you up to date information about cystic fibrosis and what it means to be a carrier.

**Are you pregnant? Thinking of getting pregnant? Recently pregnant?**  
[Please take our survey](#) to tell us about your experiences in cystic fibrosis genetics.

**OB/GYNs, Midwives, other providers of prenatal care**  
[Please complete our survey](#) to describe your current practices in cystic fibrosis genetic testing. Your password is provided on your postcard.

**WHAT IS A WEB-CAST?**  
A web-cast is a meeting conducted on the internet. A person can participate in these web-casts through any internet connection by visiting our website and following the directions. You will view a set of slides and hear the voices of the presenters. You can ask questions by typing them in, similar to a chat room. We will read your question and respond to them during the web-cast.

These web-casts and video conferences do not replace consultation with your physician or other medical professionals. For individualized advice and reproductive decision making, please see your physician or contact a genetic clinic.

**TO PARTICIPATE IN A WEB-CAST:**  
Please check back during the week of the web-cast for detailed information on participating in the web-cast. If you would like to ask questions during the web-cast you can type them in. We will read your questions and respond to them during the web-cast. Feel free to ask any questions – questions that you have are probably shared by others, and it is completely anonymous.



**Web-cast dates:**

- Tuesday, July 25<sup>th</sup>, 2006 at 7:00 pm
- Tuesday, October 17<sup>th</sup> 2006 at 7:00 pm
- Saturday, January 13<sup>th</sup>, 2007 at 11:00 am

*Please check back prior to these dates for links to participate in our web-cast.*

**IF YOU MISSED A WEB-CAST:**  
We will have past web-casts archived online, so you can access past web-casts, listen to the presentation and hear other participants' questions.

**IF YOU DON'T HAVE ACCESS TO A COMPUTER FOR THE WEB-CAST:**  
If you aren't able to access a computer during the times of the web-cast, you can join the web-casts at one of the following Public Health Clinics or other community resources. Identify the location closest to you and contact them prior to the web-cast to confirm your attendance.



To help answer questions regarding cystic fibrosis and cystic fibrosis genetics, we are hosting a quarterly web-cast and video conference to discuss cystic fibrosis (CF) genetics.

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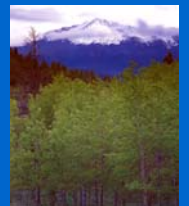
# Survey of OB/GYNs and Nurse Midwives

- Almost 10,000 postcards and emails sent out, encouraging participation in the survey
- **SIX surveys were completed**
  - All respondents All routinely offered CF testing to at least some of their patients
  - Barriers included:
    - language
    - money
    - low rate of carrier detection
    - lack of knowledge from staff about genetics
    - were nurses (5 CNMs 1 NP)



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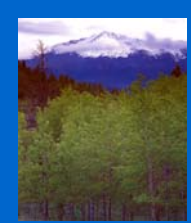
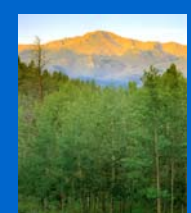
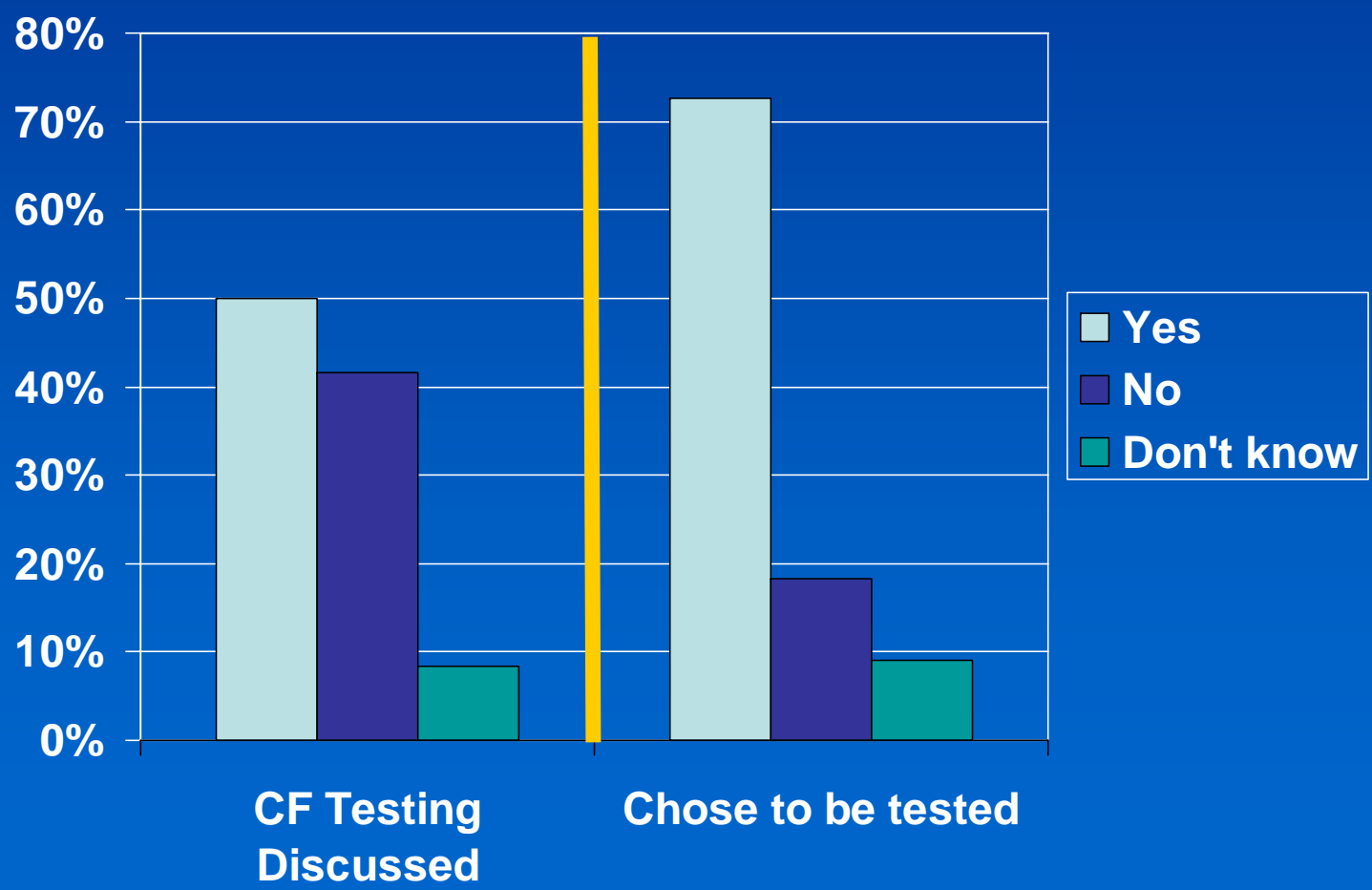
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# Survey of women receiving obstetrical care



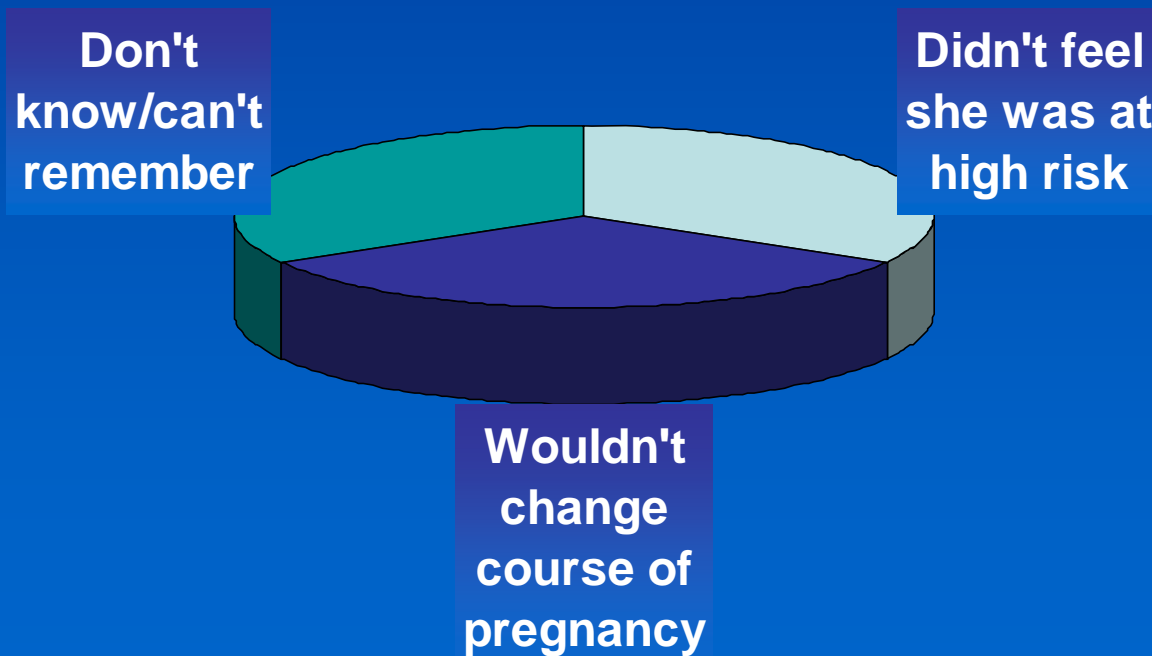
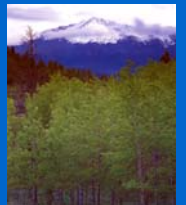
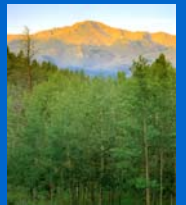
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# Why CF testing wasn't pursued



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**Cystic Fibrosis  
Carrier  
Screening**  
*"I am a CF  
Carrier,  
so NOW what?"*

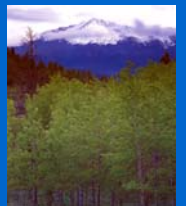
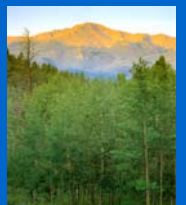
*A guide to resources  
available to CF  
carriers in Colorado*  
[www.cfcarrriers.com](http://www.cfcarrriers.com)

# Web-casts

- Invitations to participate sent to OB/GYNs to provide to interested women
- Breeze Software used, through contract at UCDHSC
  - Participants able to ask questions through 'Chat' format while viewing presenters
- Participants could also join through public health clinics throughout Colorado
- Comprehensive presentation covering natural history of CF and genetic risks
- Participation was disappointing



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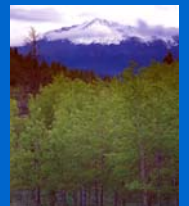
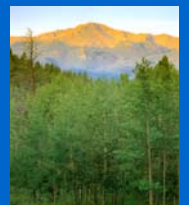
# Lessons learned

- Challenging to communicate with OB/GYNs through the mail
- Many women are not getting tested, so carriers are not identified frequently for each provider
- There is a need for better testing and counseling in the Spanish speaking population



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# Future directions

- Approaching Cystic Fibrosis Foundation to develop a tool on their website for CF Genetic Counseling
  - Especially useful as most states will be implementing CF newborn screening within the next few years



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