#### FETAL ALCOHOL SPECTRUM DISORDERS IN ADULTS: HEALTH AND NEUROBEHAVIOR

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#### The problem:

- Despite the prevalence of FASD and its life-long course, there is no empirical research about adult health, physical characteristics, neurobehavior or adaptive functioning in Middle Adulthood.
- The Developmental Origins of Health and Disease (DOHoD) hypothesis suggests that fetal programming by PAE should result in vulnerable organisms with increased sensitivity to stress, adverse health and functional outcomes.

#### THE STUDY

- Multisite Collaborative Study (part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD)
- Sites include <u>Atlanta, GA</u> and <u>Seattle, WA</u>, with a parallel study in <u>Vancouver, BC</u>.
- Two "Tier" Assessment
  - Tier 1. Demographic and Health Survey
  - Tier 2. In-Depth Assessment of medical records, physical characteristics, immune function, mental health, cognitive functioning, social/adaptive functioning







#### Emory Adult Health Study

We would like to invite everyone who has participated in one of our studies to take part in the Adult Health Study.

ADULT HEALTH STUDY ~ PART 1 If you decide to participate, you will

Example of the recruitment materials.

#### • Tier 1

Adult Health Survey (N=500) of access to health care, chronic medical problems in midlife, ages 25-45.

(Another 120 will be tested in Vancouver using the same form.)

#### Health Issues to be assessed:

- Access to health care
- Sleep
- Vision/Health/Dental
- Allergies and Asthma
- Cardiovascular
- GI
- Diabetes
- Autoimmune disorders
- Arthritis
- Seizures
- Depression/Anxiety
- Other Medical problems

#### TIER 2 ASSESSMENT

- This is intended to be an in-depth assessment of the Adults' current status. There will be several areas assessed:
  - Physical Characteristics
  - Psychological factors
  - Environmental
  - Substance Use
  - Health, including Immune Function
    - Medical records

- 120 individuals at each site (240 total) will be invited to complete this comprehensive assessment. They will be invited to the study site and will spend about 4 hours being evaluated and completing questionnaires.
- We will draw blood and take urine samples to confirm substance use reports and to allow assessment of metabolic status (A1C), liver function (GGT) and immune status.

### TIER 2 ASSESSMENT-PSYCHOLOGICAL MEASURES

- Cognitive Functioning- "fluid intelligence"
- Psychiatric Problems \_\_\_\_\_
- Substance Use \_\_\_\_\_

- NIH Tool Box
- Adaptive Functioning \_\_\_\_\_\_\_
   Adaptive Behavior Assessment System, 3<sup>rd</sup> Ed
  - Psychiatric Diagnostic Screening Questionnaire (PDSQ)
  - AUDIT, Drug Grid, Lab tests
- Life Stressors and Resources (Moos) \_\_\_\_ LISRES-2



#### **TIER 2- PHYSICAL ASSESSMENT**

- 2-D Photography taken on site
- Urine Toxicology for 7 drugs —

- Health History \_\_\_\_\_

- Dysmorphology assessment \_\_\_\_\_\_
   Evaluation by Ken Jones In collaboration with Peter Hammond
- GGT \_\_\_\_\_\_\_ Sampled in Lab
  A1C \_\_\_\_\_\_ Sampled in Lab
  Sampled in Lab
- Immune Measures \_\_\_\_\_ 
   Samples sent to Joanne Weinberg, PhD
  - Abstracted from current medical records •



#### PROGRESS

- All the Administrative hassles
  - Co-ordination among three sites to develop materials.
  - Materials Transfer Agreements
  - IRB
  - Review assessment protocol and purchase materials
  - Develop Assessment tools and database in REDCap
  - Search databases for previous participants



#### DEVELOPED HEALTH QUESTIONNAIRE

Based on the Centers For Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) Questionnaires

Modified to include modules on vision, hearing, dental problems, seizures, immune disorders, etc.

Developed by three sites.

Using REDCap system, created data entry forms that can be accessed on <u>computer</u> or <u>smart phone</u>. Can be completed by participant directly or through interview.

System is confidential and HIPAA-compliant.

Converts directly to interactive database. Can be exported in Excel or SPSS.

Multisite access.

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Piloted in Atlanta (N=10)

12/05/2017 9:54a

redcap.org REDCap

#### **IDENTIFICATION OF POTENTIAL PARTICIPANTS**

Goal: Tier 1-500 Tier 2-240

- Atlanta
- (Tier 1= 250, Tier 2=120)
  - Accessed databases from previous study waves and accumulated names, addresses, SS #; names of collaterals, Total potential subjects identified =
  - Contracted with Accurinet to allow computerized search for participants' current address, phone numbers.
  - Currently have located 60 previous participants who will be contacted when IRB completes review of recruitment materials.

*Potential problems for recruitment process:* 

Participant mobility. May have moved out of area.

No longer in "phone book". Cell phones don't have white pages.

Privacy concerns. People are much more worried about privacy than they were previously and may not answer phones.

Not interested in participating

#### Seattle

#### (Tier 1= 250, Tier 2=120)

- Accessed databases from previous study waves and accumulated names, addresses, SS #; names of collaterals, Total potential subjects identified = 433
- Contracted with TransUnion (TLO) to allow computerized search for participants' current address, phone numbers.
- Currently have located 125 previous participants; so far 65 are interested in being in this new study. All will be contacted after IRB completes review of recruitment materials.

#### TIME LINE

- Tier 1- Years 1-4
  - December 2017: Complete Administrative Requirements/ Develop Forms and Questionnaires/Recruitment Materials
  - January 2018: Initiate recruitment, Health Surveys, Registry
- Tier 2- Year 2-5
  - January May, 2018: Obtain all materials, permissions, identify initial sample
  - July 2018: Begin Tier 2 Assessments



# Development & Evaluation of an Evidence-Based Mobile Health Caregiver Intervention for FASD

Christie L. M. Petrenko, Ph.D. & Cristiano Tapparello, Ph.D. CIFASD Report - 12/20/2017







## **FMF** Connect Team



Christie Petrenko, Ph.D. MHFC / U. of Rochester



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12/20/2017

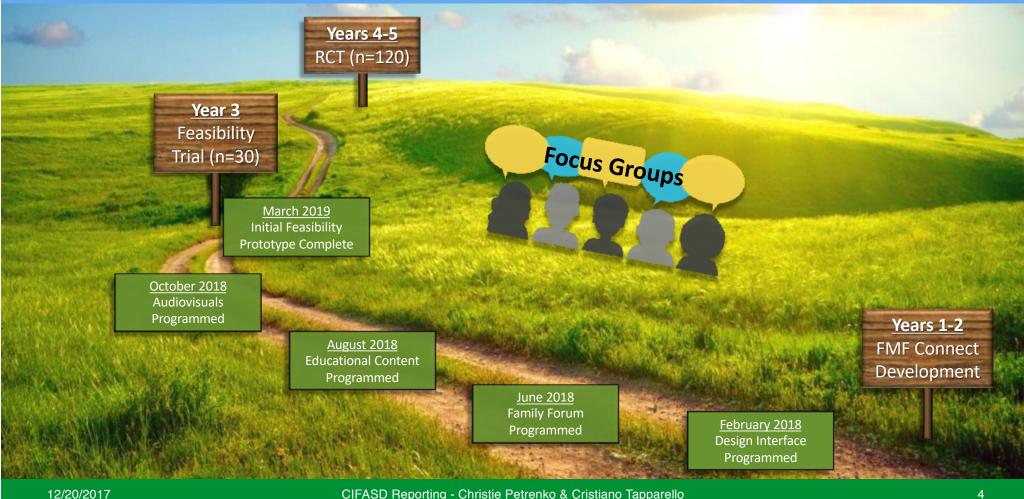
CIFASD Reporting - Christie Petrenko & Cristiano Tapparello



## **FMF** Connect Components



## **Project Timeline Overview**



Families Moving Forward

CIFASD Reporting - Christie Petrenko & Cristiano Tapparello



## **Content Development Process**

- Families Moving Forward Program content, principles, methods
  - FMF developed by Heather Carmichael Olson and team at UW/SCRI
  - Funded by CDC
- FMF Connect is a derivative product with unique features
- Informed by multiple fields:
  - Translating content and principles across methods of delivery
  - Education/online learning: Backward design process
  - Implementation science: Behavior change techniques
  - Ethical considerations

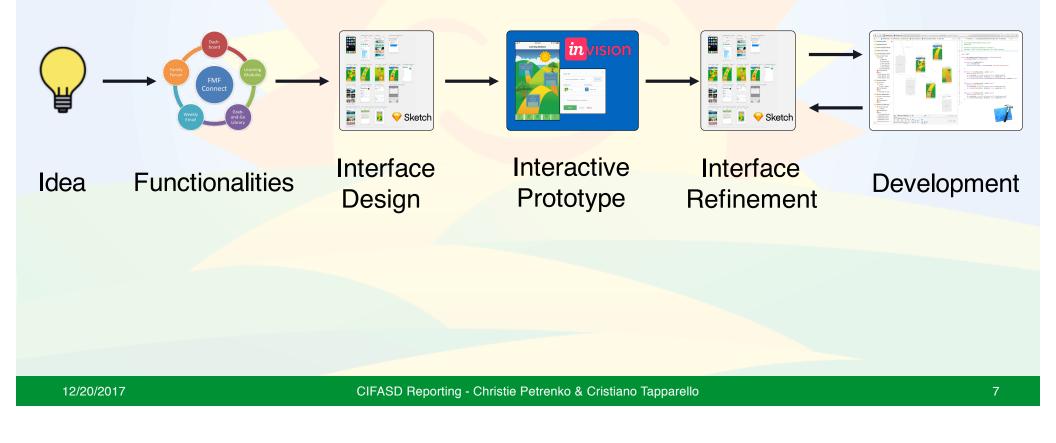


## **Developing Content Progress**

- Update on content development progress:
  - 12 core modules all drafted (~ 100 pgs), 1<sup>st</sup> round intense editing complete (> 64 hrs), revisions in process
  - Drafting optional content, compiling materials for library
- What's next?
  - 2<sup>nd</sup> round editing review core content, 1<sup>st</sup> review of optional materials
  - Programming content and exercises in app
  - Elicit feedback on content in focus groups
  - Scripting and producing audiovisual content



## App Design Process





## App Design Progress (1/5)

 App idea consolidated during grant writing/submission



App idea

12/20/2017

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## App Design Progress (2/5)

**\_** –

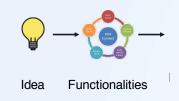
Families Moving Forward

#### Idea

- App functionalities identified during grant writing
- Refined while working on the app content



## App Design Progress (3/5)



Families Moving Forward

- Mockup app idea and functionalities into a set of screen images
- Facilitate feedback and discussion across team



### **Interface** Design



## App Design Progress (4/5)

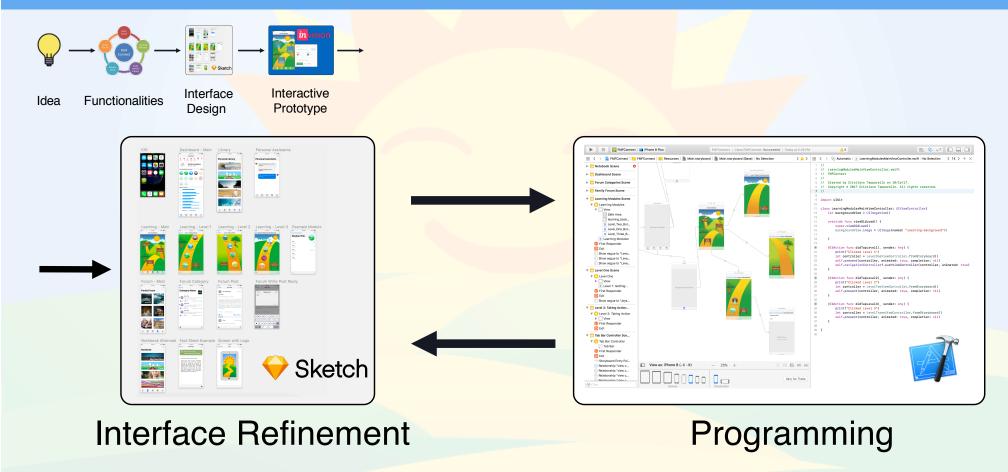


- Combined the different screens into an interactive prototype
- Demonstration in focus groups



### Interactive Prototype

## App Design Progress (5/5)



Families Moving Forward



## App Programming Progress

- App requirements:
  - Cross-platform (iOS, Android, web?)
  - Authentication, security, modular structure, cloud functionalities, real time synchronization, push notifications, analytics, etc.
- Open source products
  - Google Firebase
  - ResearchKit and Carekit
  - ResearchStack and ManageMyCondition





## App Programming Progress

- Initial implementation of the InVision prototype on iOS
- Forum development:
  - Cloud database structure
  - Authentication
  - Read and write operations from app
  - Real time synchronization
- Current work in progress:
  - Interface to fully match prototype
  - Forum: messages organized in thread (replies), avatar



## Focus Groups

- Diverse perspectives: family structure, comfort with technology, location, child age, etc.
- Initiated focus groups in Rochester 12/6 and 12/8
- Planning additional groups in:
  - Rochester (periodically) \*including with and without prior FMF exposure
  - Washington DC (Mitchell) ? emphasis on birth parent perspective
  - Atlanta (Coles) ~ March
  - Minnesota (Wozniak) ~ April
  - San Diego coincide with RSA in June

### **CONNECT** Preliminary Findings from Initial Focus Groups

#### Components

- Felt strongly users should be able to use app indefinitely to return to helpful content and engage with forum
  - Liked that app content of interest could be saved to Notebook for later reference
  - Positive about tools in Notebook; suggested additional tools
- Trust, confidentiality, and protections were major themes for Family Forum
  - Suggested access to specific sub-forums be introduced as users complete relevant learning modules
  - Liked idea of having sub-forums available based on geographic location (sharing resources/advocacy tips)
  - Want easy way to aggregate and find tips/resources suggested by other users

### Preliminary Findings from Initial Focus Groups

- App & Interface Design
  - Strong, positive reaction to learning module interface design
  - Less enthusiasm for logo/icon, but generally neutral to positive
  - Prefer graphics to photos
- Facilitators to use

Families Moving Forward

- <u>Content/Features</u>: When child is struggling; connecting to other users
- <u>Technology</u>: Voice-to-text; transition across platforms (e.g., phone, computer)
- Barriers to use
  - <u>Content/Features</u>: poorly moderated Family Forum, concerns of trust/safety
  - <u>Technology</u>: difficulty to navigate; lots of scrolling; slow loading





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