

Illinois Department of Children and Family Services  
**Institutional Review Board Meeting**  
**Minutes**  
**January 5, 2022**

**ON PHONE**

Janet Ahern  
Robin Albritton  
Christina Chojnacki  
Tami Fuller  
Kim Mann  
Robin LaSota  
Dr. Margaret Scotellaro  
Brooke Taylor

**CALL TO ORDER**

Janet Ahern called the meeting to order at 3:11 p.m. A quorum was present.

**APPROVAL OF MINUTES**

Tabled until next month.

**FOLLOW UP**

**Robert Foltz.** *Residential Intervention & Outcome Trajectory for Youth in Care*

Provide email information

**MOTION:** Dr. Margaret Scotellaro motioned to approve the proposal, pending the results of the restriction request.

Kim Mann seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

**NEW PROPOSALS**

**Ellen Chadwick.** *PH 100: Surveillance Monitoring for ART Toxicities Study in HIV-uninfected Children Born to HIV-Infected Women (SMARTT Study) Version 5.0 dated 8/16/2016*

Do we include the biological parents in the studies? Longitudinal study.

Good quality work that is supported. A point in the study where you need to agree to continue. If you have a healthy child that is doing well, you may not want to continue to do so.

Have recent status reports been submitted? Parent has the ability to withdraw or continue. Guardian's office should be included because it's changing the medical care of the child.

Which kids that are in care that are still involved in the study. Making sure that the Guardian's office is involved in the study or get the parents opinion (and the Guardian's opinion). Contact Janet for consent

if the children come into care. They should inform both the Medical Director AND the Guardian's office. Then it can be decided whether to reach out to the parent or not.

Study is adding an extra drug above a standard of care. Side effects are well understood and monitored. And stopping a drug when the standard of care is continuing indefinitely (which is continuing to suppress the HIV).

Conditional approval, but if the child comes into care and we need a consent form for the different level or stage, they would need to notify the Medical Director and Guardian's Office.

**MOTION:** Dr. Margaret Scotellaro motioned to conditionally approve the proposal, based on the caveat proposed.

Robin Albritton seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

**Ellen Chadwick.** *P1115: Very Early Intensive Treatment of HIV-Infected Infants to Achieve HIV Remission: A Phase I/II Proof of Concept Study Version 2.0, dated September 2018.*

Do we include the biological parents in the studies? Longitudinal study.

Good quality work that is supported. A point in the study where you need to agree to continue. If you have a healthy child that is doing well, you may not want to continue to do so.

Have recent status reports been submitted? Parent has the ability to withdraw or continue. Guardian's office should be included because it's changing the medical care of the child.

Which kids that are in care that are still involved in the study. Making sure that the Guardian's office is involved in the study or get the parents opinion (and the Guardian's opinion). Contact Janet for consent if the children come into care. They should inform both the Medical Director AND the Guardian's office. Then it can be decided whether to reach out to the parent or not.

**MOTION:** Dr. Margaret Scotellaro motioned to conditionally approve the proposal, based on the caveat proposed.

Robin Albritton seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

**Mary Clyde Pierce.** *The Epigenetic Impact of Abusive vs Accidental Head Trauma in Young Children: A PILOT Study.*

Been around for a while. Not sure what she's studying but what is she getting from the swab in the mouth.

Epigenetics is fairly new – can alter your DNA to not pass along genetics. How does your life experiences affect your genetic code. Looking at mRNA for indicators of changes to children's DNA. Very complicated study that may be making a lot of big jumps in the science. Study is a bit overwhelming.

Just an observational study. A lot of factors that go into it. Struggle with the waivering of consent with the families that are having a child abuse investigation. Could be abusive injuries in the control group as well, because they are not being investigated. Unsure why a parent would agree to that when that could be the end result. Worried about some bias that could be introduced there.

Didn't understand the confidentiality of the waiver program. What are the procedures for the waiver of consent.

PILOT Study, which is just exploratory at this point. This is just descriptive information that she is collecting. Isn't an intervention study that is being presented.

**MOTION:** Brooke will contact the researcher regarding presenting at the next meeting around questions that the board has regarding the proposal. Will ask her to walk us through the research proposal.

**Jamine Dettmering.** *Effects of Validation on Responding during Escape Extinction.*

Is the whole proposal based on ABA? Yes. This is the treatment that they are implementing.

Researcher has indicated that she has access to youth in care now, but requires DCFS IRB approval before she can recruit.

Is Escape Extinction something that we would use? Is the behavior a reflection of trauma? Not against behavioral approaches.

There are no benefits to the study. Small enough and esoteric enough, this is not going to be a great benefit to the Department. Kids can be in the therapy without being in the study.

**MOTION:** Robin LaSota will follow up with the researcher to find out where she is recruiting the youth in care from and design questions/

**Amy Dworsky & Veena Ramaih.** *Evaluating the MPEEC Program – AMENDMENT.*

Not interviewing children – just interviewing caseworkers. Want to see if MPEEEC involvement decreases the length of conclusion of a case. Likelihood that it will be reversed on appeal. Looking at investigator satisfaction.

**MOTION:** Kim Mann motioned to conditionally approve the proposal, based on the caveat proposed.

Robin LaSota seconded the proposed motion, Christina Chojnacki abstained from the vote and a unanimous vote from the remaining board members carried the motion.

**Dana Weiner.** *Illinois Family First Prevention Services Act: Evaluation of Trauma-Focused Cognitive Behavioral Therapy.*

Consents are asking for medical information. For this one, the provider is DCFS. Families still retain legal authority over their children.

**MOTION:** Tami Fuller motioned to approve the proposal.

Dr. Margaret Scotellaro seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

**Dana Weiner.** *Illinois Family First Prevention Services Act: Continuous Quality Improvement Process MI and MST.*

No discussion.

**MOTION:** Tami Fuller motioned to approve the proposal.

Dr. Margaret Scotellaro seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

**Jallah Wilson.** *Turnover and Youth Outcomes.*

Just contacting caseworkers. No data for youth in care, no identifying information. Is she relying on the caseworkers to provide her with the numbers. 8 permanency workers that are volunteers. Is caseload data public data?

Researcher is an intern doing internal CQI. Student can keep the work product that is gathered from their internship. Data that she is using is non-identifiable. Just using caseload numbers.

Is this for publication or for her master's thesis?

Doesn't say if she is recording these interviews at all. Not mentioned in the consent form. Assumption is that there is not going to be a recording – so is she going to be taking really good notes? If we allow her to record our caseworkers, can we specify what it can and can't be used for? The consent would be just for the purpose of this study. Will they be removing names from the transcripts and where will they be storing the recordings? How are they going to be keeping it safe and secure.

Researcher cannot access other cases outside of her research. What kind of SACWIS access does the researcher have to the files?

**MOTION:** Brooke will follow up with the researcher regarding the questions posed by the board.

**OTHER:**

**Ellie Bruckner Manuscript.** Really good study. Very interesting report.

**Operations Addition:** Wendi Ingersoll will be invited to the next meeting.

Next meeting scheduled for January 25, 2022 at 3 PM.

The meeting adjourned at 2:46 pm.