

Evaluating Vitamin D Levels in Children with PKU: From Project Inception to Data Collection

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LEND Trainee

LEND Leadership Project

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The End?

Available Data

- PKU Clinic at Center on Human Development and Disability begin assaying children's vitamin D levels January 2009
- All children with PKU in Washington state followed at this clinic
- Medical records from birth available
- Monthly diet records available

Study Justification

Why would we care about vitamin D levels in children with PKU?

Literature Review

- Phenylketonuria (PKU)
 - Genetic disorder
 - Inability to break down phenylalanine (Phe)
 - Incidence of 1:15,000 births in Washington state
- Vitamin D
 - “Sunshine vitamin”
 - Many biological roles
 - Bone health
 - Chronic diseases

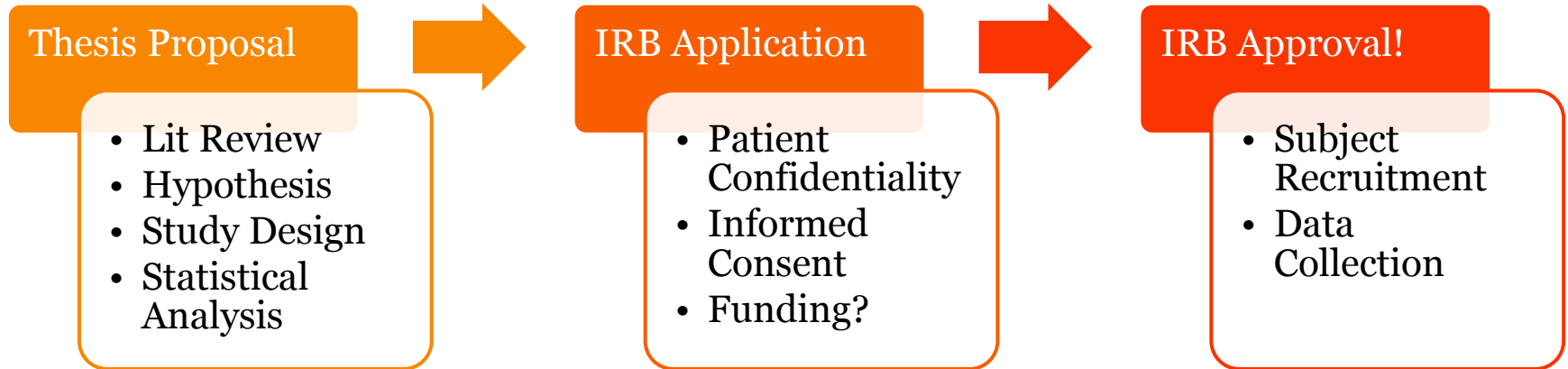
Forming the Hypothesis

- PKU and vitamin D – what's the connection?
 - Children with PKU must limit Phe consumption
 - Phe is found in protein
 - PKU diet
 - Low-Phe protein formula
 - Very low food protein
 - Main dietary vitamin D source in Western diet = fortified milk
 - Milk consumption very limited in PKU diet

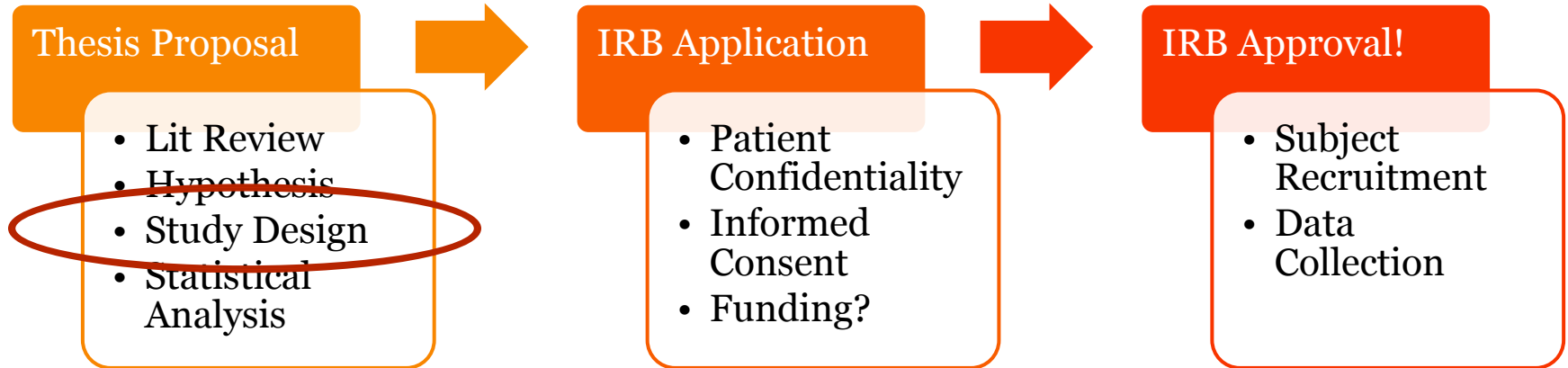
Research Questions

- Are children with PKU at greater risk for vitamin D deficiency than children without PKU?
- Is there an association between PKU diet compliance and vitamin D status?

Roadmap to Data Collection



Roadmap to Data Collection



Study Design 1: Sibling Control

- Advantages
 - Control for factors affecting vitamin D levels
 - Latitude
 - Season
 - Sun screen use
 - Assay technique
- Disadvantages
 - Require funding
 - Clinical Research Budgeting and Billing (CRBB)
 - Set up study budget to prevent double-billing
 - Blood draw from pediatric population
 - Complex
 - Research Testing Services (RTS)
 - Keep paperwork, specimen for PKU and sibs separate

Study Design 2: Medical Record Review

- Advantages
 - Minimal risk
 - Likely quick IRB approval
- Disadvantages
 - Not all vitamin D drawn during same season
 - NHANES data as control
 - Different vitamin D assay (HPLC vs. DiaSorin)
 - Different latitudes, seasons

Final Study Design

- Prospective medical record review
- Weaker design, but...
 - Preliminary study
 - Masters level thesis
 - Easier to carry out
 - Set ground work for future research

Current Status

- Vitamin D assays completed on 46 children in 2009
- Study pending IRB approval

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