

Presentation at CTSA Consortium Steering Committee (CCSC) Annual Meeting Oct 8-9, 2009

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- Purpose
 - Introduce CCSC to mission and activities of CC-CHOC
 - Review CC-CHOC accomplishments
 - Outline 2, 7 and 20 year goals
 - Propose better approaches to enhance child health participation in CTSA consortium efforts

Key Accomplishments

- CC-CHOC well-aligned with CTSA strategic goals and key functions
 - Pediatric Research Ethics Working Group (PREW) linked to both CC-CHOC and Clinical Research Ethics Working Group
- Creative group providing opportunities to pilot promising initiatives on a smaller but nationwide scale (an “incubator”)
 - Multi-center IRB proposal presented to SACHRP and pilot planned
 - Metrics of Success initiative
 - Virtual biorepository for rare diseases project
- Active partnerships already in place
 - NICHD supported BPCA Awards
 - Alliance with Pediatric Academic Societies

Two Year Goals

- Multi-center IRB model implemented and tested on several trials
- Institution specific metrics of success benchmarks established
- Established prioritization models for pediatric drugs and devices
- Establishment of a virtual biorepository for utilization by rare disease groups
- Contribute child health core competencies to the SGC standard curriculum

Seven Year Goals

- National infrastructure including data management tools, support services and policies for networks to conduct multi-center trials
- More emphasis on life span research with collaborations across all ages (child to adult health) to focus on prevention of adult disorders and better defining antecedents of adult disease (e.g. obesity)
- Additional metrics of success that include the impact of research on improved child health
- Increased number of young faculty developing careers in pediatric clinical and translational sciences
- Strong emphasis in child health across all CTSA's

20 Year Goals

- Robust child health research community with senior faculty in leadership positions and junior faculty eager to develop their careers in clinical translational science
- Personalized medicine with focus on prevention of childhood disorders and childhood antecedents of adult disease (e.g., obesity, hypertension, cancers). Research studies spanning the entire lifespan from children to adults (already done in CF)
- Established minimally invasive, cheap and valid outcome measures that are age-specific, thereby increasing the speed and efficiency of pediatric drug/device development
- More precise understanding of what is a “normal” child both in terms of genotype and phenotype
- Better health for children worldwide as a result of successful research discoveries moved into action

Key Outcomes of CCSC Meeting

- Increased visibility of CC-CHOC creating opportune time to
 - Talk to CTSA leadership at your site about child health programs
 - Link up with KFC's
- Increased focus on issues important to child health
 - Rare diseases
 - Lifespan research
- Created a better linkage between CCSC and CC-CHOC for ongoing communication and collaboration

Upcoming CC-CHOC F2F Meeting Vancouver BC, April 30, 2010

- CC-CHOC Annual Face to Face Meeting 8am-12pm at hotel (TBD) near Vancouver Convention Center
- CC-CHOC first annual workshop 1-5pm – same location
 - Topic “Informatics – *State-of-the-Art* Skills and Applications”
- Support for meeting based upon R13 proposal – “Linking CTSA Sites to Improve Pediatric Research”
- If R13 is not accepted, we will have the same program but establish a registration fee for all participants (\$50-\$100)

PAS Meeting

Vancouver BC, May 1-4, 2010

- Three symposia accepted
 - CTSA's: Changing the Environment for Pediatric Translational Research Chairs: Ramsey and Barkin
 - CTSA's: Regulatory Challenges in Pediatric Research Chairs: Sokol and Guay-Woodford
 - Joint session with APA – Translating Research into Practice Chairs: Leslie and Kemper
- Two abstract sessions
 - Theme – Informatics
 - All CTSA related research should apply
- Fellow/trainee support will not be possible unless R13 is funded
- Individual programs may choose to support travel funds for young investigators who have abstract accepted for presentation

Reminder Abstracts Due November 18!



- Send a reminder letter out to CTSA members, pediatric faculty, etc. at your site
- Remind everyone to check off “Clinical Translational Science Award” as the topic area!
- Thank you to CC-CHOC members who volunteered to review abstracts and be moderators of sessions