

**CTSA Consortium Child Health Oversight Committee (CC-CHOC)
Quarterly Web Meeting
August 6, 2009
Meeting Summary**

Time: 3:30 PM – 5:00 PM ET

Meeting Recording URL: <https://webmeeting.nih.gov/p32083222/>

CTSA Attendees: B. Ramsey (Univ. of Washington, Chair); S. Barkin (Vanderbilt, Chair-Elect); S. Arslanian (Pittsburgh); J. Cody (San Antonio); J. Davis (Tufts); S. Denne (Indiana); L. Epstein (Northwestern); J. Fowles (Arkansas); D. Gipson (North Carolina); J. Gurney (Michigan); D. Hagler (Mayo); D. Hale (San Antonio); J. Hall (Stanford); P. Harris (Vanderbilt); B. Hay (UC Denver); J. Heubi (Cincinnati); C. Huskins (Mayo); M. Jessup (Michigan); D. Johnson (Chicago); S. Kashyap (Columbia); F. Kaskel (Albert Einstein); J. Li (Duke); C. Lowery (Arkansas); C. Marcus (Penn/CHOP); S. Massie (North Carolina); E. Mendonca (Chicago); J. Murray (Iowa); E. Neufeld (Harvard); J. Perrin (Harvard); J. Puck (UCSF); G. Retsch-Bogart (UNC); L. Ross (Chicago); C. Sandborg (Stanford); K. Scott (Vanderbilt); R. Sokol (UC Denver); M. Stein (Chicago); J. Vockley (Pittsburgh)

NIH Attendees: E. Collier (NCRR); X. Heng (NCRR); S. Hirschfeld (NICHD); K. Kidd (NCRR); M. Purucker (NCRR); Y. Rubinstein (ORDR); F. Bowen (Booz Allen PM)

Please note, all presentations are posted online at

http://www.ctsaweb.org/index.cfm?fuseaction=meeting.viewMeeting&year=2009&com_ID=27#mtg_ID_1527

I. Welcome to new CC-CHOC members from 2009 CTSA cohort and Review of CC-CHOC 2009-2010 goals (Dr. Bonnie Ramsey, Chair)

Dr. Ramsey welcomed the new 2009 CTSA cohort, and asked new CC-CHOC representatives to email [Farrell Bowen](mailto:Farrell.Bowen@boozallen.com) upon joining the committee.

Institution	Location	PI
University of Arkansas for Medical Sciences	Little Rock	Curtis L. Lowery, MD
University of Illinois at Chicago	Chicago	Theodore Mazzone, MD
University of Cincinnati (Spring 2009)	Cincinnati	James E. Heubi, MD
University of Florida	Gainesville	Peter W. Stacpoole, MD, PhD
Mount Sinai School of Medicine	New York City	Hugh A. Sampson, MD
New York University School of Medicine	New York City	Bruce Neil Cronstein, MD
Medical University of South Carolina	Charleston	Kathleen T. Brady, MD, PhD
University of Texas Medical Branch	Galveston	Allan R. Brasier, MD

An overview of the CC-CHOC was provided, beginning with the mission statement of the CC-CHOC, which is to “provide a unique national forum to identify collaborative opportunities to facilitate child health clinical and translational research.” The CC-CHOC goals are:

- Building partnerships (e.g., PAS, NICHD)
- Building infrastructure (e.g., shared resources)
- Developing standard approaches (e.g., optimizing outcome measures)
- Identifying and overcoming barriers (e.g., multi-center IRB review)

All members meet quarterly by webinar and annually face-to-face in conjunction with the PAS meeting. An Operations Group (elected by membership) meets monthly by teleconference and Working Groups meet as needed. The current workgroups are as follows:

- Pediatric Drugs and Devices (Co-chairs Jennifer Li, Carole Marcus, Steven Hirschfeld)
- Pediatric T2 Research (Co-chairs Alex Kemper, Eneida Mendonca)

- Metrics of Success (Chair: Shari Barkin)
- Pediatric Research Ethics (Co-chairs: Steven Hirschfeld, Alex Kon)
- Rare Diseases (Nancy Green, Bob Steiner) New chairs TBD

The 2009-2010 CC-CHOC priorities are the following:

- Enhancing alignment with Strategic Goal Committees
 - Setting child health priorities for committees
 - Actively engaged in consortium, administrative supplements and pilot projects
- Enhancing partnerships to further child health clinical and translational research
 - Further develop PAS partnership
 - Collaborations with NICHD
- Enhancing training and education
 - R-13 conference grant submission
 - Child health focus for core curriculum
- Defining metrics for success in child health
 - Implementation of proposed metrics
 - Develop annual "Progress Report"
- Encouraging linkages with existing child health research networks

II. 2010 Pediatric Academic Society (PAS) Meeting (Dr. Bonnie Ramsey, Chair)

This year the PAS meeting is in Vancouver, BC on May 1-4, 2010 and three submitted CTSA symposia have been accepted with two potential CTSA abstract platform sessions. For the PAS abstract program, an abstract review team will be established around September 1st. Last year abstract review was handled by the Operations Group, and this year we would like other volunteers to assist in review of abstracts, which will be between November 25 and December 14. Volunteers are also needed to moderate the Abstract Sessions. Every CTSA should ideally submit 2-4 abstracts by November 18.

III. Child Health Core Competencies (Dr. Bonnie Ramsey, Chair)

The CTSA Strategic Goal Committee 2: Training & Career Development of Clinical/Translational Scientists have developed core thematic areas and competencies that are currently under review and will be finalized in the next few months. The CC-CHOC will review these core competencies and ensure there is a child health and developmental focus in the curriculum. If anyone is interested in this effort or has developed a clinical and translational research curricula focused on pediatrics, please email [Dr. Ramsey](#) or [Farrell Bowen](#).

IV. R13: Linking CTSA's to create effective collaborations to improve child health (Dr. Shari Barkin, Chair Elect)

The CC-CHOC leadership is submitting an application for a three year conference grant to support the annual CC-CHOC F2F meeting as well as activities held in conjunction with the PAS. The proposal describes three main objectives:

- Build and share expertise of CC-CHOC investigators across CTSA sites
- Expand reach of expertise to scientists attending the PAS meeting
- Provide a CTSA fellowship program to promote multi-site collaboration

The three key thematic areas proposed for each year of support are as follows:

- Year 1: Informatics
- Year 2: Community Engagement
- Year 3: Life continuum research

The format consists of a Workshop with experts in the field, minimum of two Symposia integrated into the PAS meeting, Abstract sessions, a CTSA Child Health Research Fellow Award and promoting interaction between junior and senior investigators across CTSA sites. Abstracts submitted from the

CTSAs that would be considered responsive include activities sponsored by the CTSA or that directly benefit from CTSA resources including the GCRCs; we are particularly interested in the thematic area of bioinformatics for Year 1.

V. Metrics of Success (Dr. Shari Barkin, Chair Elect)

The Metrics of Success are finalized, as follows:

1. CTSA grant funding for child health research
2. IRB-approved and funded child health research
3. Number of child health trainees/faculty who have received mentored grants
4. CTSA child health research pilot grants
5. Active child health studies in CRC
6. Child health research conducted in collaboration with other CTSAs
7. Child health research investigator participation in institutional leadership
8. Institutional-unique approaches for added value in child health research

The next steps will be to distribute the Metrics of Success to the CTSA sites and have a CC-CHOC institutional point person gather the data. After data is gathered, it will be submitted to a CC-CHOC executive committee to collate starting benchmarks and examine variation across sites. Data will be de-identified so individual site identification will not be possible. The metrics will also be provided to external advisory committees.

VI. CTSAweb.org and the CTSA Wiki (Dr. Kameha Kidd)

Dr. Kidd provided a brief overview of the public website, CTSAweb.org, including the committee information on the left panel, the Regional Consortia pages, and the "Consortium Login" link to the [CTSA Wiki](#). The CTSA Wiki highlights include multimedia training videos on [CTSA Main](#), Wiki spaces for each committee, the CTSA wiki unified calendar, and the Committee Participant Management (CPM) System. Through the CPM system, Administrators and PIs or other designated official can add their institution's participants to committees. Visit the Wiki for more information, and contact the CTSA Help Desk, Help@ctsaweb.org, if you have any technical difficulties accessing or using the Wiki.

VII. Upcoming Workshops and Administrative Supplement Update (Dr. Steven Hirschfeld)

The Data Acquisition Workshop has been rescheduled for February 25, 2010 (originally scheduled for August 27, 2009). The focus will still be pediatrics, but the agenda planning team will ensure it has a broad appeal across the CTSA Consortium. To plan the workshop, CC-CHOC will work with other CTSA committees who have an interest in the topic. More information will follow in the near future.

The November 18-19, 2009 workshop, "Methodologies to Set Priorities for Child Health Clinical Research" will be held at the Natcher Auditorium (NIH campus) and videocast. The goals will be exploration, discussion and development of approaches to establish priorities for child health clinical research studies, particularly in the area of development of pharmaceutical products that meet the needs of children. There will be a series of open agenda planning teleconferences for anyone interested in contributing to the content or planning the workshop agenda. Dates, times, and call-in information will be announced in the near future.

The Research on Outcome Measures for Pediatric Clinical Trials in support of BPCA supplement applications have been reviewed and scored. There were many applications submitted. Applicants will be notified by the end of this month.

Additionally, Dr. Hirschfeld has been named Acting Director of the National Children's Study (NCS). Dan Hale and Jeff Murray are the CC-CHOC members who have built the alliance between the CTSA and the NCS. If anyone is interested in using the NCS as a platform for specific, longitudinal studies in specific age groups, please contact [Dr. Hirschfeld](#).

VIII. National Recruitment Registry: ResearchMatch (Dr. Paul Harris)

Dr. Paul Harris from Vanderbilt University presented an overview of ResearchMatch.org, which is “a national partnership to create a centralized, web-based recruitment registry that will connect willing volunteers with researchers and their studies.” This work was supported through a CTSA administrative supplement, funded in 2008. It has completed beta-test and will have its Phase 1 launch in September 2009. To date, this project has engaged 36 of the then 39 CTSA in the planning efforts. Dr. Harris offered additional details about the program objectives and described the tool's eight-step process in providing “both participating sites and volunteers with information regarding research findings and utility of recruitment tool.”

The next steps include completing Phase 1 of review, and developing an effective marketing plan prior to the launch in September 2009.

For more information about ResearchMatch, please contact the Program Coordinator, [Kirstin Scott](#).

IX. Workgroup Updates

Note: To join a CC-CHOC workgroup or for more information, please email [Farrell Bowen](#).

Pediatric Research Ethics Workgroup (PREW) Update (Drs. Friedman-Ross and Hirschfeld reporting on behalf of Dr. Kon)

The Pediatric Research Ethics Workgroup (PREW) has been gathering information and examining approaches to the Institutional Review Board (IRB) process for pediatric multisite studies in a systematic fashion that included two conferences, on September 11, 2007 and April 23, 2009. Following input from the conferences and a presentation and discussion with the Secretary's Advisory Committee on Human Research Protections on July 21, 2009, the PREW is preparing to implement a pilot project of a federated model for linking IRBs through an operations center and aligning IRB practice through a compact that outlines the principles, process and performance expectations of IRBs that volunteer to participate in the federation. Anyone interested in the topic is invited to join the effort.

T2 Research (Dr. Eneida Mendonca)

The two new co-chairs, Alex Kemper (Duke) and Eneida Mendonca (Univ. of Chicago), were announced. Additionally, a schedule change with teleconferences alternating between the 4th Wednesday and Thursday of the month will allow greater group participation. The meetings will continue to be from 4 to 5 PM ET, starting with Wednesday, August 26.

The plan for the upcoming year is to have the workgroup members participate in those CTSA groups that are preparing white papers/reports related to T2 research to assure that issues related to child health care are addressed and provide a mechanism to share the work of these other groups with the pediatric research community.

Rare Diseases (Dr. Jennifer Puck)

The goals of the Rare Diseases Workgroup are to be a platform for communication, collaborative research, education and training; and a platform for providing resources to RD researchers and trainees. Challenges/Issues identified are the following:

- Inadequate patient numbers at individual sites
- Many rare diseases not covered in existing networks
- Infrastructure needed to organize multi-center efforts
- Biorepositories exist, but little coordinated information
- Limited number of both current and future investigators
- Need for multi-center training mechanisms
- Coordinating functions with the multiple other RD groups

The Workgroups activities to date include developing relationships **with** other child and adult rare disease groups, both research and advocacy/patient; a CTSA-sponsored project on Distributed Biobanks for Rare Diseases (DBRD) led by Dr. Jennifer Puck (UCSF); Peter Merkel (BU) leading an R13 application through NINDS for a training day in rare disease research (funding decision pending); and a nascent virtual library of relevant documents and resources (e.g. protocols, consent forms, other) posted on the CTSA wiki for general use.

The Workgroup is due for change of leadership. The CC-CHOC is now inviting nominations to chair or co-chair the Rare Diseases Workgroup. Please nominate yourself or confirm willingness of your chosen nominee prior to submitting the name for consideration. Include a 2-sentence statement of interest and send to [Farrell Bowen](#) by Sept. 8, 2009. Nominees with an interest in pediatric or adult rare diseases are both encouraged to apply.

X. CTSA Consortium Updates (Dr. Mary Purucker)

Dr. Purucker introduced herself as the NCRR Coordinator for the CC-CHOC and echoed the congratulations and welcome to the 2009 CTSA's. The CTSA Consortium Steering Committee (CCSC) incoming co-chairs are Harry Shamoon (Albert Einstein), Becky Jackson (Ohio State), and Julian Solway (Univ. of Chicago). The outgoing co-chairs are Gordon Bernard (Vanderbilt) and Garrett Fitzgerald (Penn). The change of leadership will occur in January 2010. Additionally, the CC-CHOC has been asked to provide a presentation at the CCSC face-to-face meeting on October 8-9, 2009 in Rockville, MD.

XI. Action Items

#	Action Items	Owner	Due Date
1	New 2009 CTSA CC-CHOC members, email Dr. Bonnie Ramsey or Farrell Bowen	New 2009 CTSA's	
2	Submit at least 1 abstract (ideally 2-4) to the PAS Abstract Program under "CTSA Supported Pediatric Clinical Translational Research"	All CTSA's	November 18, 2009 (opens Sept 1)
3	Volunteer for PAS Abstract Review Team or to be an Abstract Sessions Moderator. If interested, e-mail the CC-CHOC Chair, Dr. Bonnie Ramsey	Any interested CC-CHOC participant	
4	Volunteer to work on the Child Health Core Competencies project	Any interested CC-CHOC participant	
5	To be added to a Workgroup, email Farrell Bowen	Any interested CC-CHOC participant	
6	Self nominate or nominate others for Rare Disease Workgroup Chair by submitted a 2 sentence statement of interest to Farrell Bowen	Any interested CTSA participant	September 8, 2009
7	Prepare for CC-CHOC presentation at the CCSC face-to-face meeting	Chairs, Dr. Purucker	October 8-9, 2009