

## Meeting Minutes June 20, 2007

**In Attendance:**

Bonnie Ramsey

Ben Wilfond

Brian Saelens

Cate Pihoker

Danielle Zerr

Diana Borchardt

Eileen Klein

Heather Carmichael Olson

Jackie Starr

Janet Englund

Jerry Zimmerman

Jonathan Perkins

Julie Brown

Julie Park

Karen Murray

Lynn Rose

Heather Lindemann

Delila Katzka

By Phone -

Pam Joy

**Introduction:**

After brief introductions, Bonnie began the meeting by giving some background for those who had not been involved in the previous session. She mentioned her overview presentation and how the team had progressed in drafting the vision statement. She then described the task for today which includes developing the centers' strategic priorities including the organizational, functional and program areas.

**Center name:**

The possibility of changing the center's name was floated for comment. Committee members felt that adding childhood or pediatric to the title would be beneficial. After a brief discussion, the team decided to revise the center name to:

**Research Center for Pediatric Clinical and Translational Science**

**Vision statement refinement:**

They then turned to the draft vision statement and made some minor revisions. Bonnie took the action to edit the vision keeping in mind the team's input. The revised version is below:

**VISION:**

We will be one of the premier centers in the country to conduct clinical studies leading to better medical treatments of children as well as understanding the mechanisms of disease. Our research center is the critical bridge to translate new scientific discoveries emerging from our partners in other Institute centers into novel therapeutic approaches that will potentially prevent or cure childhood diseases. We will advance the science of clinical research by focusing on research methods, ethics, and the mentoring of tomorrow's leaders. We have the specialized expertise and resources to conduct large national and international clinical studies while maintaining focus on the unique needs and well being of each child.

**Priorities:**

The team looked over the handout containing draft priorities from the other centers and a list of those previously identified by this team in order to launch the discussion. In addition, Lynn Rose, a member of the leadership group for the proposed CTSA program grant , provided an overview of some of the grant's resources that might tie in with the discussion. CTSA (Clinical Translational Science Awards) is an NIH supported program involving the University of Washington and its affiliated institutions to provide infrastructure for clinical and translational investigators. They have space where you can conduct clinical research, but the charter is much broader including infrastructure such as bioethics, biostatistics, community outreach, lab services, and others. Several Pediatric faculty are in leadership roles in the CTSA including Drs. Ramsey, Melvin, Rosenfeld, Rose, Tarczy-Hornoch and Wilfond. Bonnie stressed that it is important that the center be a conduit to this program.

Some of the things for which the center might want to partner with CTSA include:

- Streamlining communications and collaboration so that Children's Research Institute can better integrate with CTSA.
- As a clearing house for communication
- Providing a route into the labs from the outside
- Symposiums

The team then brainstormed priorities both in terms of what is needed and in terms of barriers that exist that need to be addressed:

Collaboration:

1. Resources to facilitate networks
  - a. Disease networks
  - b. Updates
  - c. Registry
  - d. Nationally and locally
2. Collaborate with the University including Pharmacology, Genetics, Functional imaging, Bioengineering, Biostatistics, Global Health, School of Public Health, etc.
3. Collaborate with others institutions including Group Health, Virginia Mason.
4. Collaborate with other centers at Children's Research Institute.
5. Partner with surgery and radiology in participating and providing service to research grants, specimen collection and storage.
6. Develop a seminar series – works in progress.

Funding:

1. Identify grants with sharing opportunities (program grants) within and across centers.
2. R34 training award (to develop a program for post fellowship training)
3. Targeted grant alerts (someone to sort and sift)
4. Target multiple sources of funding including industry, foundation and federal sources.

Barriers:

1. Cross institutional contracts - major barrier
2. Post award management currently supported by institute
3. Pre-award support (grant writing support, technical editors)
4. Improved charging practices that avoid duplicate charges and unnecessary red tape

Personnel needs:

1. Defining work content and promotional ladders for research personnel
2. Salary ranges
3. H.R. oversight – balance of PI with OCR oversight
4. Training
5. Identify space for personnel near patients, not at MetPark
6. Maintain a critical mass of support personnel (supplemental funding and bridging support) providing 24 hour/7 day coverage
  - a. Types of personnel:
    - i. Research coordinators (project management)
    - ii. Research nurses
    - iii. Dietary, nutrition support
    - iv. Data entry/management
    - v. Lab processing
    - vi. Translator services
    - vii. Personnel to to conduct questionnaires and surveys – psychometrics

Other:

1. “Clinical research without walls” – multiple sites for clinical research; offsite locations for healthy subjects.
2. IRB (though much improved) can improve more
3. Identified space for center.

Program:

1. Cores:
  - a. Regulatory
  - b. Imaging and analysis
  - c. Laboratory for specimen processing and banking
  - d. Biostatistics
  - e. Data management
  - f. Patient advocacy and education (a public face for the center to interact with patients and the community)
  - g. Nutrition
  - h. Sleep center
  - i. Exercise
  - j. Inflammation
  - k. Phenotype and genotype (hospital based, routine mechanisms to collect specimens, store and access data) – this center to develop, facilitate and own this process
  - l. Bioethics
  - m. Research pharmacy and distribution center

- n. Pharmacokinetics core with necessary assay development capabilities
- o. Health related quality of life measure (questionnaire support)

**Further discussion:**

The following individuals were identified as potential collaborators in the strategic planning process: Dennis Shaw & Fred Hoffer for functional imaging. It was also noted that if Joe Rutledge is unable to attend the next meeting that possibly Karen Tsuchiya or Raj Kapur could fill in at the meeting.

To conclude the meeting the committee was asked to review the priorities and add to and/or edit them as necessary after which, the team will be requested to rank them. Priorities will be finalized at the next meeting which is scheduled for Friday, June 29 from 9:00-11:00 a.m. at the hospital, conference room W3747B.

**Action:** Review priorities list and add additional as needed. **(Committee members)**

**Action:** Refine vision based on discussion in today's meeting. **(Ramsey)**

**Action:** Send out priorities for review and additions. **(Katzka)**

**Action:** Collect committee responses to priorities review and develop a ranking survey Distribute to the group and compile results. **(Katzka/Lindemann)**

Submitted by:

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