

Meeting Minutes June 29, 2007

In Attendance:

Bonnie Ramsey
Ben Wilfond
Brian Saelens
Cate Pihoker
Dennis Mayock
Eilleen Klein
Elizabeth McCauley
Jackie Starr

Jerry Zimmerman
Joseph Flynn
Ken Jaffe
Lynn Rose
Margaret Rosenfeld
Sam Mokowitz
Diana Borchardt
Heather Lindemann
Delila Katzka

Introduction:

Heather reviewed what has been done so far and discussed the next steps in the process. Today we need to go through the list of strategic initiatives developed at the last session in order to summarize them so that they can be stated at a higher level. Afterward we will need to rank them but this can be accomplished electronically after the meeting. Today, we will also define your program priorities, though these do not need to be ranked.

After we complete these tasks we will put together a draft document and circulate it for edits and comment. This needs to be completed within the next two weeks so that Bruder can present all of the centers' strategic plans to leadership in July. In August there will be a two hour public forum dedicated to this center where Bonnie will present your draft and provide opportunity for discussion and feedback. The forum is scheduled for August 17 from 9:30 to 11:30 a.m. Everyone is welcome to attend including outside collaborators. Please invite anyone that you think would like to participate. After the forum we will go back and incorporate the feedback and then finalize the document.

The subject of overlap in strategy among centers was brought up. Bonnie explained that the center directors were aware that there are areas where it makes sense to share resources and will work together to accomplish some of these goals. Member are encouraged to look at the research web site where they will find the minutes from the other committee's meetings and can see what they are preparing. The web page is <http://research.seattlechildrens.org/centers/research-center-strategic-planning.asp>.

Vision statement refinement:

The team made minor changes to the vision statement. The revised and accepted version is below.

VISION:

We will be one of the premier centers in the country to conduct clinical studies leading to better understanding and treatment of childhood 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 and improve functional outcomes. 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. We will advance the science of clinical research by focusing on research methods, ethics, and the mentoring of tomorrow's leaders.

Priorities:

The committee then reviewed some priorities from previous strategic planning and developed the seven high level items. These were generally accepted as the priorities under which the more detailed items from the last meeting could be grouped. Heather will send out a survey to determine ranking. It was noted that these were all very important and it will be difficult to rank them, but it was also noted that ranking them will help with further planning and decision making.

Strategic priorities (not ranked):

1. We will be leaders in the design and conduct of clinical research for all aspects of pediatric medicine.
2. We will create the infrastructure including state of the art facilities and exceptional research staff for the safe and efficient conduct of research involving children.
3. We will be a leader in promoting a greater understanding of the ethical aspects of pediatric clinical research through our ongoing collaboration with the Treuman Katz Center.
4. We will partner with families and communities to enhance communication about clinical research and to guide our research initiatives.
5. We will attract world class investigators, support current investigators, and nurture future leaders through mentoring and seed funding.
6. We will foster close collaboration between clinicians and basic scientists to efficiently translate scientific discoveries into future pediatric therapies.
7. We will partner with CTSA and other local, national and international investigators in the development of new clinical outcomes measures, study designs, and statistical methodologies optimizing clinical research involving children.

Program priorities:

The following program priorities were developed by the committee. There was discussion about including focus areas for clinical research, but the committee decided that this would distract from our goal to meet the clinical research needs of all pediatric investigators. They did agree to work on focus areas at a later date, perhaps highlighting different investigators and programs in a more informal way on the web site.

Program priorities (not ranked):

1. Development, implementation and conduct of clinical trials for all pediatric diseases
 - a. Pharmaceutical
 - b. Biologics

- c. Devices
 - d. Preventative therapies
 - e. Pharmacokinetics
 - f. Diagnostics
 - g. Behavioral interventions
 - h. Educational interventions
 - i. Novel study design and analytic methodologies
2. Clinical trial endpoint development
- a. Biomarkers
 - b. Short-term and long-term functional outcomes
 - c. Imaging
 - d. Economics
3. Clinical characterization of patient cohorts that promotes investigation of:
- e. Genomics
 - f. Proteomics
 - g. Metabolomics
 - h. Environmental factors
 - i. Personal factors
- } ...and the interactions among those factors
4. Translational drug and device development
- a. Regulatory consultation and clinical development planning
5. Research subject advocacy and ethics
- a. Investigator and participant education
 - b. Communicating outcomes to participants
 - c. Assessing participant experience
6. Clinical research education and compliance for investigators and staff

Next steps:

The committee will be asked to respond to a survey in order to rank the strategic priorities. Once the ranking is complete the final document will be drafted and circulated for comment. Please plan to attend the forum in August. Please let Bonnie know if you would like to participate on a panel for that event.

Action: Respond to survey and participate in the final document preparation. **(Committee members)**

Action: Survey committee to rank strategic priorities. **(Katzka/Lindemann)**

Action: Group the more detailed items under the higher level strategic priorities. **(Ramsey/Lindemann)**

Submitted by:

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