

# Pediatric Care at the NIH Clinical Center Hospital



# Charge provided to the CWG



Review and assessment of the NIH Pediatric Planning Group Report (April 29, 2022) entitled “Pediatric Care at the NIH Clinical Center”.

The CWG was asked to assess:

- 1) Possibility of increasing volumes of children cared for at the CCRH.
- 2) Lowering the age from 3 years to 6 months

**“patient safety being of paramount importance”**



# Charge provided to the CWG – Questions posed

Specific questions posed were:

- 1) Is the platform for early-in-human clinical trials employing the Clinical Center's business model a significant addition to the research landscape for children?
- 2) Can they provide safe care employing the partnership model?
- 3) Is the partnership model proposed feasible?
- 4) Are the approximate costs realistic?
- 5) What have they failed to account for in the model?



# Process undertaken – Initial Meetings



The CWG in its advisory role met remotely several times to discuss the report's recommendations. The initial meeting consisted of the large group followed by sub-group meetings that reviewed the plans for:

- 1) the proposed pediatric intensive care unit (PICU) and emergency services
- 2) Pediatric Subspecialty needs
- 3) Needs assessment for rare and genetic childhood disorders warranting first-in-human clinical trials.

# Process undertaken – NIH CC Visit

CWG advisory sub-group members (Devaskar, Bogue, Clapp and Silverman) made an onsite visit to the NIH Clinical Center Research Hospital on 12/14/22 to meet:

- Members of the Clinical Center
- NIH principal investigators
- Jennie Lucca, CEO of the Children's Inn
- Dr. Schor, Deputy Director of Intramural Research
- Dr. Gilman, CEO of the NIH Clinical Center
- Nursing leadership and nurses
- Pediatric and other relevant hospital leaders
- Critical Care physician leaders and other leaders

The group also toured the relevant areas of the Clinical Center where children are cared for (mental health and neuropsychological testing area, and outpatient and in-patient pediatric areas)

# Process undertaken – Post Visit

Based on these meetings and the site visit, the Advisory Group identified **strengths** and areas of focused improvement required to overcome anticipated **challenges** that may emerge as a result of the PPG's recommendations for the care of pediatric patients at the Clinical Center.



The CWG focused on suggestions for improving the delivery of clinical care for pediatric patients at the NIH Clinical Center and addressed gaps that existed in the report.

# CWG Report – Identified Strengths of Proposal

- 1) Proposed Expansion in the number of children enrolled in clinical trials at the NIH Clinical Center will help facilitate evaluation of first-in-human trials for rare diseases.
- 2) Surveys of the Institute Clinical Directors indicated that future state could see a marked increase in the number of children 0-3 years old who are admitted to the inpatient (2 to 3-fold) and those children requiring critical care (6-fold).
- 3) The suggested approaches in the proposal for pediatric emergency management (“codes”) is appropriate.
- 4) The recommendations for a PICU, if the decision is made to establish one, incorporate a number of best practices.
- 5) Establishing and formalizing the positions of PICU medical director, nurse manager and Clinical Nurse Specialist (CNS)/educator, are major strengths of the plan.

# CWG Report – Identified Strengths of Proposal

- 6) Contracting with a partner academic institution to provide pediatric intensivists who will provide and direct patient care in the PICU is appropriate.
- 7) The proposal to establish contract services for sub-specialty consult services is appropriate.
- 8) Proposal to not lower the age from 3 years to 6 months at once, but rather stage it gradually as the PICU capabilities increase and team competency is assured (e.g. first to 2 years, then 1 year and then 6 months).
- 9) Recommendations related to creating a child- and family-friendly environment for the care of children.
- 10) Children's Inn is a major asset
- 11) The emphasis on changing blood collection policies and practices to minimize blood loss for children is extremely important.



# CWG Report – Identified Challenges and Gaps

- 1) Feasibility of maintaining staff and provider competency and adequate staffing for a 3-bed PICU.
- 2) Difficulty in maintaining adequate staffing when the pool of staff is quite small.
- 3) Need 24/7 coverage by Pediatric Intensivists/Pediatric hospitalists with cross-training of pediatric nurses to increase the pool and competency of staff.
- 4) The need for a well-functioning robust quality and safety program.
- 5) Prospectively identifying conditions that will not be treated at the NIH CC PICU or treatment modalities that will not be used, necessitating transfer to the PICU at another institution.
- 6) Need for acquiring the necessary equipment for the PICU that is Pediatric-centric, including alarm settings etc., and routinely tested and maintained for the use in children.



# CWG Report – Alternative Approach

If it is determined that it is not desirable/feasible to establish a PICU at the NIH CC, an alternative approach is to conduct the NIH studies at other children's hospitals/academic medical centers.

- **Advantage:** all of the infrastructure required to care for critically ill children, even those enrolled in research studies, is in place at many children's hospitals, both free-standing and part of larger health systems.
- **Potential Disadvantage:** it would separate the NIH intramural scientists with expertise in the diseases and potentially new treatments from the patients who are part of the clinical trial, which can be mitigated by engaging the intra-mural scientists in such consortia with extramural investigators

# CWG Report – Proposed Budget Feasibility



Proposed budget feasibility would depend on the model that is developed and the contractual agreements reached.

CWG suggests sharing a **Request for Applications** with local institutions with larger PICUs in place, to obtain full buy-in from a partner institution and commitment to the CC PICU and Pediatrics.

# CWG Members



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# Questions