Aman Kumar - Written evidence (PRT0035)

(1) My name is Aman Kumar. I was born at 24-25 weeks' gestation in the United States 37 years ago, and after various roles in global software companies and startups I am now a private investor. Birth before 26-28 weeks is termed *micropremature*, and my experience is that of an "adult survivor of micropremature. This evidence is submitted in a personal capacity.

(2) There is a pernicious myth in the United States medical system that those born early experience "catch-up growth" after neonatal intensive care (NICU) or childhood. This is not the case. My medical team now refers to my condition as "multi-organ damage" or "multi-organ immaturity," a syndrome affecting many major organ systems chronically. The effect is generally of the following types: organs have less capacity, are more prone to injury, healing takes longer or is incomplete, and age-related decline is earlier and more rapid. I have been informed that "premature aging is the late price of premature birth," with genetic (telomere) testing reflecting a "prematurely-aged phenotype."

(3) Certain aspects of developmental immaturity can be quantified and predicted. For example, a kidney at 24 weeks only contains ~100,000 nephrons, versus ~1-1.5 million nephrons at 36 weeks; no further nephron growth occurs after birth. Therefore adults born at 24 weeks must live life with 10-15% the kidney capacity of their term peers, leading to potential chronic kidney disease (CKD) and kidney failure as they age. Similarly, most maternal calcium is absorbed by the fetus in the third trimester of gestation; preterm birth therefore leads to potential osteoporosis. Most development of the autonomic nervous system likewise occurs in the third trimester, leading to potential dysautonomia, and so on. These and other already known and quantifiable areas should be specifically targeted for policy and testing

interventions.

(4) There is a chasm between adult and pediatric medicine in the United States, such that the doctors with the most expertise in these developmental conditions become inaccessible to patients after they turn 18 for legal and insurance reasons. In my personal experience, few adult pulmonologists are familiar with bronchopulmonary dysplasia, the lung disease of prematurity. Few adult nephrologists know about kidney development, or the potential coming explosion of CKD patients within this population. Few adult cardiologists are familiar with *small* heart chamber sizes, since heart disease often presents as an enlargement, or about "impaired pulmonary vascular development" that must be detected and addressed early to prevent fatal disease like adult-onset pulmonary hypertension. Adults born preterm are thus subject to a lifetime of hunting for the right adult doctors, hoping that those doctors might have the time and open-mindedness to learn from their pediatric specialist counterparts.

(5) It is essential to develop policy and testing specifically for preterm-born children and adults, and especially those born micropremature. Tests such as pulmonary spirometry, VO2 max/exercise testing, iohexol tests of kidney function, bone density scans, etc. not only guide pediatricians towards possible early interventions (age 1-10), but they serve as baselines against which to evaluate subsequent injury, infection, and age-related decline later in life.

(6) Because prematurity is so heterogeneous and its effects so randomized, an increased focus on this population can help the rest of the medical system further develop "precision medicine," in which the medicine is tailored to the context of the individual and their circumstances. It may also help the medical system develop models for care through the life course, breaking down silos between specialties and between adult and pediatric medicine.

(7) While the above observations have been written generally, I am

available to discuss further specifics privately as needed. Thank you for your investigation of this important topic.

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