GABRIELLA MILLER KIDS FIRST PEDIATRIC RESEARCH PROGRAM

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Working Group Co-Chair

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Presidential Election Campaign
Check here if you, or your spouse if filing jointly, want $25 to go to this fund. Checking a box below will not change your tax or refund. [ ] You [ ] Spouse
Signed into law on April 3, 2014
Ended taxpayer contribution to presidential nominating conventions
Transferred remaining $126 million into the Pediatric Research Initiative Fund
Authorized appropriation of $12.6 million per year for 10 years to the NIH Common Fund for pediatric research; first appropriation was for FY2015
NIH Common Fund

- Run by the Office of Strategic Coordination, Office of the NIH Director
- Trans-NIH programs involving multiple NIH Institutes
January 2014 – A Trans-NIH Working Group consisting of Dr. Collins, other IC Directors, and NIH staff considered the challenges and opportunities for transformative pediatric research.

Ideas coalesced around the need for a pediatric data resource consisting of well-curated clinical and genetic sequence data.

Focus on pediatric cancers and structural birth defects.

Leadership by NICHD, NHLBI, NHGRI and NCI.
Kids First Common Fund Working Group

- Trans-NIH Structural Birth Defects Working Group: NICHD, NHLBI, NHGRI, NIAAA, NIAMS, NIDCR, NIDDK, NIDA, NIEHS, NINDS, OD/ORIP
- NCI’s Pediatric Oncology Preclinical & Clinical Programs
- Bioinformatics Specialists
- Extramural research community stakeholders
- Advocacy Communities
Overall Goal

To develop a data resource for the pediatric research community of well-curated phenotype and sequence data that will help determine the biological basis of structural birth defects and childhood cancers

- Cohort identification and enrichment
- Data Resource development integrating genomic and other data with community portal
- Pilot projects using the data resource to mine, aggregate, link, and analyze data

*Limited funds mandate focused effort*
FY 2015 Initiative

- PAR-15-259  Discovery of the Genetic Basis of Structural Birth Defects and of Childhood Cancers: Gabriella Miller Kids First Pediatric Research Program (X01)
  - An administrative supplement will be awarded to an NHGRI-funded sequencing center
  - X01 (Resource Access Award) soliciting for WGS structural birth defects cohorts (trios), childhood cancer cohorts (trios) with a suspected genetic basis, and samples of treatment-resistant sarcomas (to jumpstart FY16 Precision Medicine Initiative)