Funding Opportunity Announcement Number PAR-24-082 10th Cycle

Marcia Fournier PhD
Pre-Application Webinar
Friday, February 2, 2024

https://www.youtube.com/watch?v=U6Tq85GSg3g

The Kids First program is now accepting applications **to submit samples for sequencing**

National Institutes of Health
Office of Strategic Coordination–The Common Fund

Agenda

- About the Program
- Application Guidelines
- Kids First Resources
- Q&A

Kids First Program Origin

Gabriella Miller's Pediatric Cancer Advocacy Empowering Research Across Pediatric Conditions

Oct 2013 - Gabriella Miller, childhood cancer advocate, died at age 10 from an aggressive brain cancer.

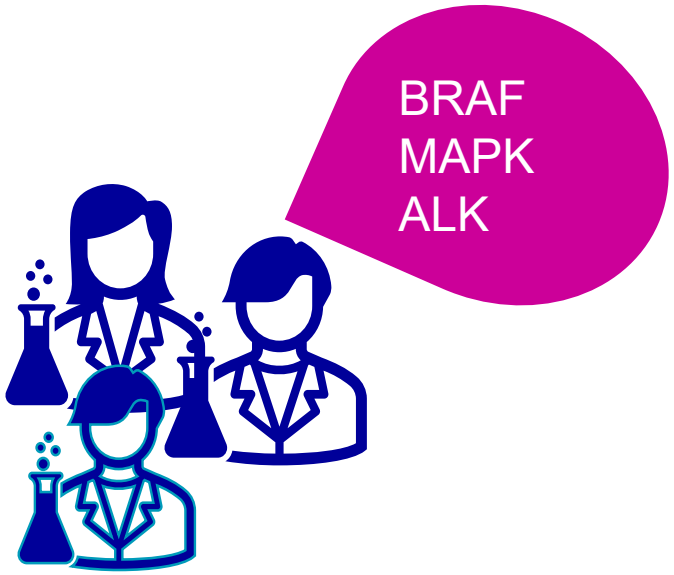
April 2014 - Gabriella Miller Kids First Research Act authorizes $12.6 million/year for 10 years to NIH for pediatric research.

Vision:

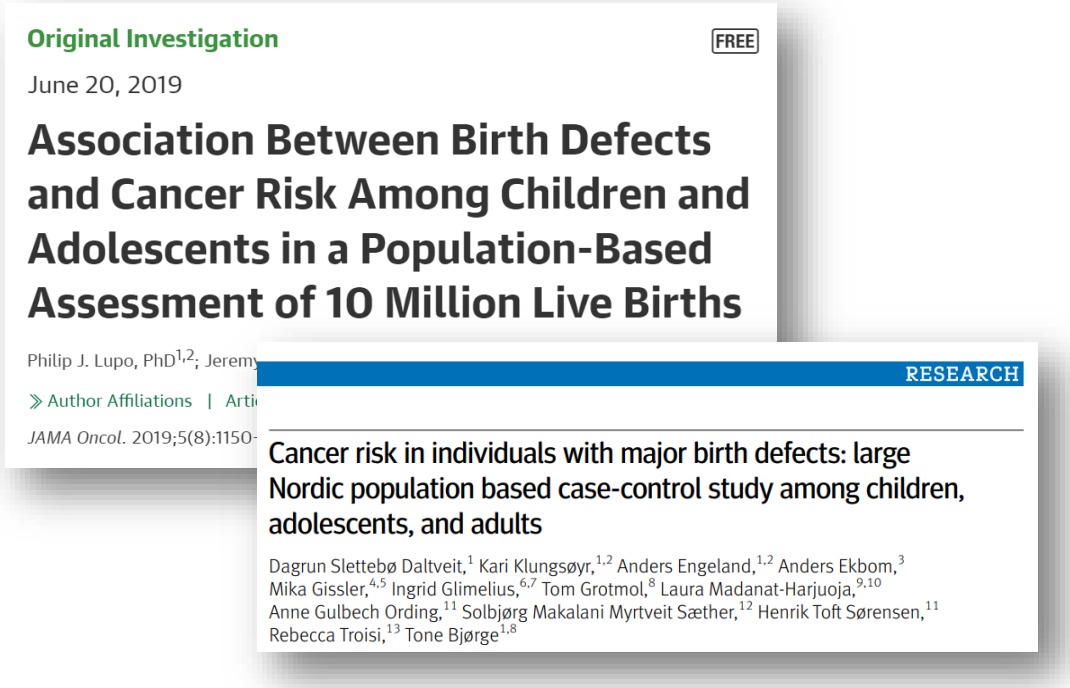
"Alleviate suffering from childhood cancer and structural birth defects by **fostering collaborative research** to uncover the etiology of these diseases and **supporting data sharing** within the pediatric research community"

Association Between Structural Birth Defects and Childhood Cancer

Shared mutations and drug targets across pediatric conditions



Cancer risk increased among children with birth defects


Original Investigation FREE

June 20, 2019

Association Between Birth Defects and Cancer Risk Among Children and Adolescents in a Population-Based Assessment of 10 Million Live Births

Philip J. Lupo, PhD[1,2]; Jeremy

Author Affiliations | Arti

JAMA Oncol. 2019;5(8):1150-

RESEARCH

Cancer risk in individuals with major birth defects: large Nordic population based case-control study among children, adolescents, and adults

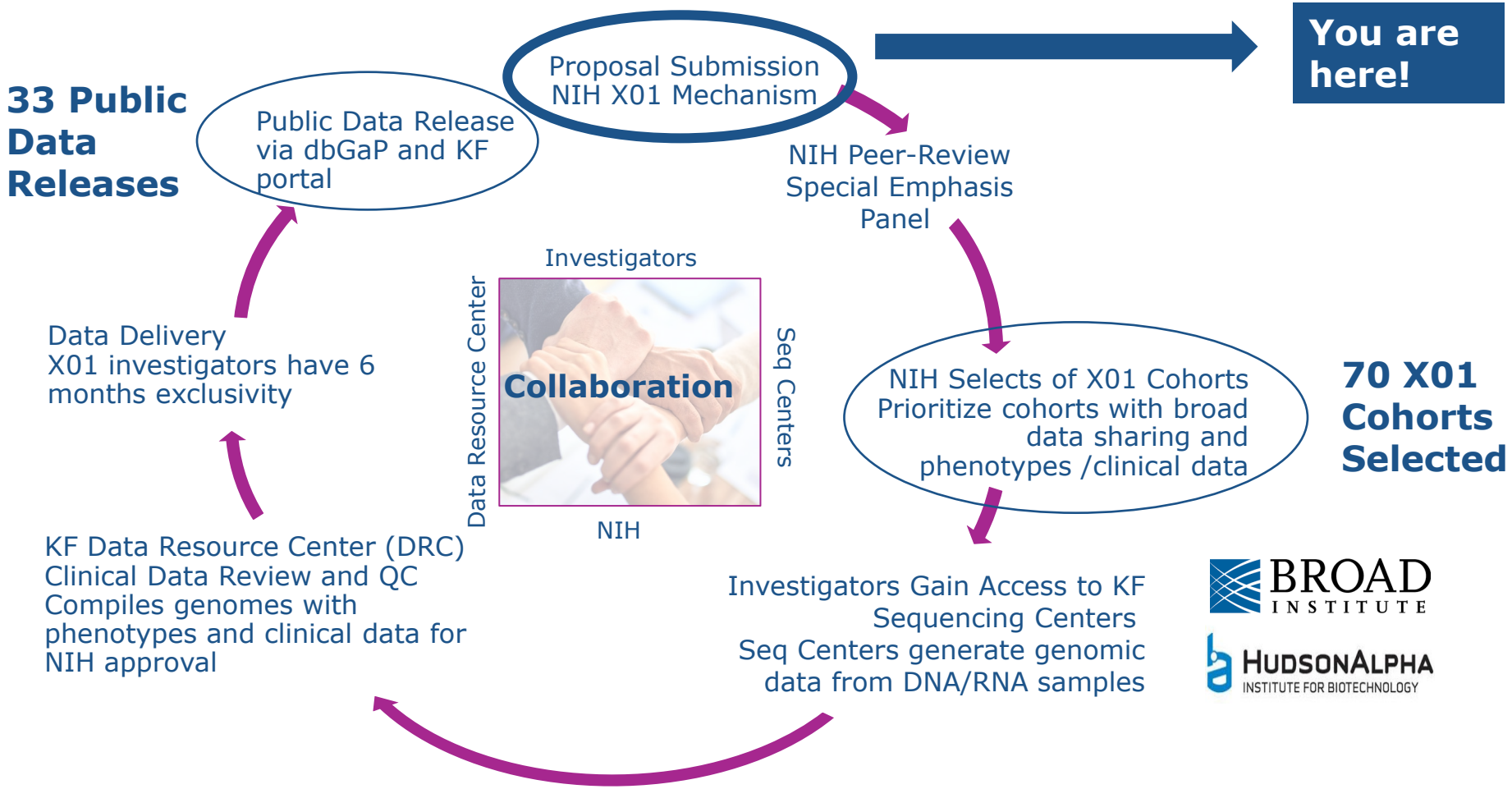
Dagrun Slettebø Daltveit,[1] Kari Klungsøyr,[1,2] Anders Engeland,[1,2] Anders Ekbom,[3] Mika Gissler,[4,5] Ingrid Glimelius,[6,7] Tom Grotmol,[8] Laura Madanat-Harjuoja,[9,10] Anne Gulbech Ording,[11] Solbjørg Makalani Myrtveit Sæther,[12] Henrik Toft Sørensen,[11] Rebecca Troisi,[13] Tone Bjørge[1,8]

Kids First Current Priorities

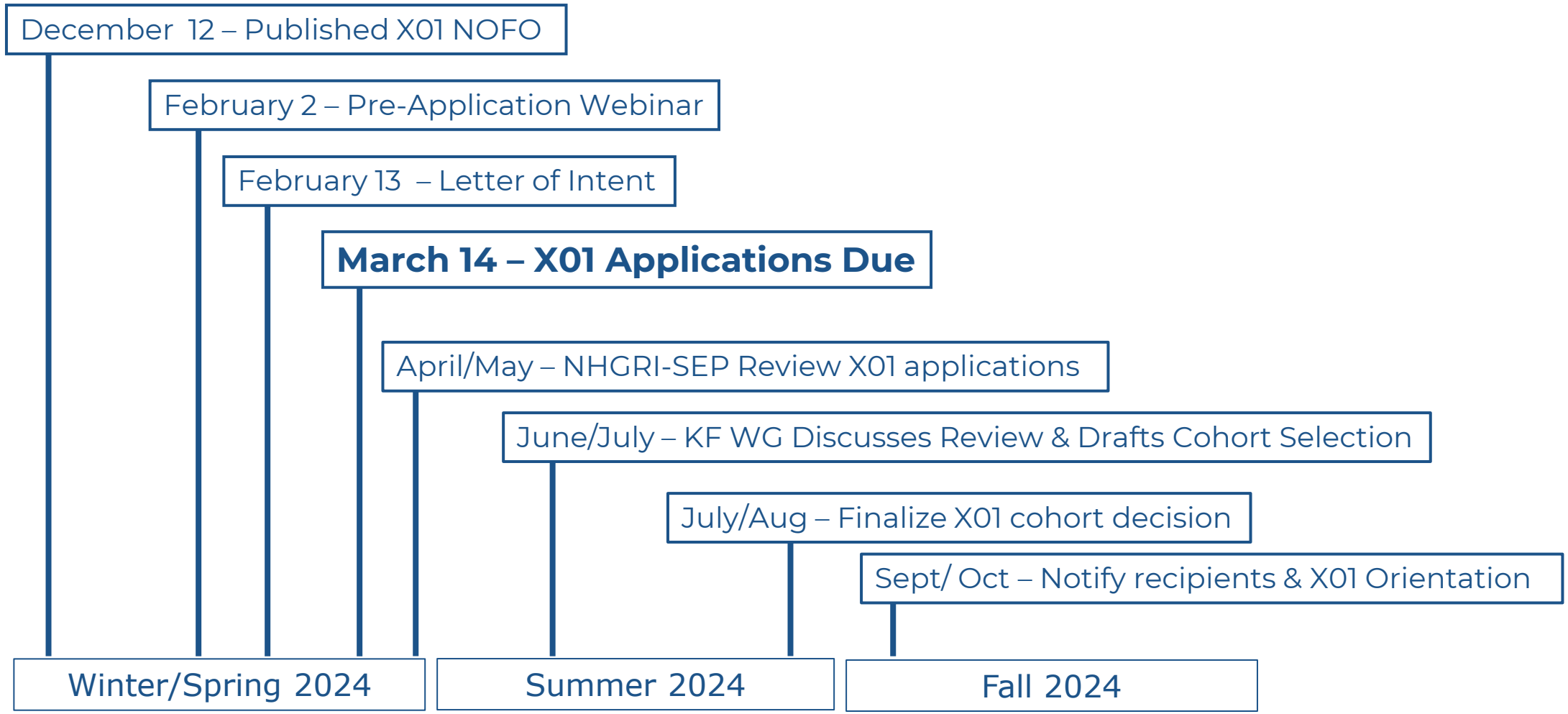
Funds Available: $12.6-25 million per year

- Add more –omics data types of childhood cancer and structural birth defects
- Development of the Data Resources
- Support expert-driven research activities to increase the value of Kids First data

Kids First Data Generation Cycle: Empowered by X01 Mechanism, Genome Sequencing Centers, and Data Resource Center. All Starts with Patients Cohorts



PAR-24-082 Timeline



PAR-24-082 Highlights

- Data sharing is critical to Kids First and the entirety of the X01 application, but there is no requirement for a separate Data sharing plan.
- Research plan remains a requirement
  - Representation, diversity, and inclusion are encouraged
  - Description of cohort, family tree, phenotypes, and clinical information remains a requirement
  - Description of genomic data sharing through the Kids First Data Resource Center portal remains a requirement
- Other attachments remains a requirement
  - Institutional Certification (or provisional certification with data use limitations designations)
  - Sample Information
  - Clinical/Phenotypic Data
  - Family Structure (Optional)

Sequencing Centers

Goal:

- Generate high quality whole genome sequence and variant data from childhood cancer and structural birth defects cohorts.

Expectations:

- DNA samples must be of sufficient quality and concentration for WGS or Long Read PacBioRevio.
- RNA samples (for tumor/affected tissue) must be of sufficient quality and concentration for RNASeq.
- Samples will be ready to ship by the end of calendar year.

See Appendix for Sequencing Centers services and sample requirement

Study Design

Goal:

- Study design, sample size, and family structures are sufficient to lead to genetic discovery

Expectations:

- Large sample sizes preferred
  - Consider collaborating with other investigators to pool samples together
- Non-trio family designs: describe the number of probands and affected/unaffected family members proposed for sequencing

Sample Information: Fillable Table

DNA (and RNA) tissue of origin	Number of Samples	Extraction Method	Concentration	Quality (Metric used:*[edit here to specify]*)	Method of Quantitation	Number of Samples Ready to Ship by August 2019	Number of Samples Ready to Ship by January 2020
Blood							
Saliva or Buccal swab							
[other tissue, edit here to describe]. **Note: cell lines will not be accepted**							
Tumors or Affected Somatic Tissue							
DNA – Frozen Tissue							
RNA – Frozen Tissue							
DNA – Embedded Tissue							
RNA – Embedded Tissue							
Total							

*For tumor specimens or affected tissue samples, please also describe the fixation methods and the pathology review to which the specimens were subjected, separate from the table. For tumors, describe the percentage of tumor cells within the specimen used for DNA and/or RNA isolation and % necrosis.

Analysis Plans

Goal:

- Have investigators demonstrate that the proposed project has an adequate research design for genetic discovery, and that the X01 applicants are prepared to perform these analyses

Expectations:

- While Kids First recognizes that analytical power will increase when the data from each individual study is incorporated with other data that will be part of the Data Resource, it is important to demonstrate that the data will be useable on its own
- Consider partnering with other research teams with relevant expertise to develop the analysis plan
- Researchers are encouraged to use the cloud-based infrastructure, including Cavatica, for their analysis

Data Sharing

Goals:

- Make data generated by Kids First as accessible and usable as possible to the research community.
- Enable researchers to easily combine/compare datasets for cross-disease analyses.

Expectations:

- Individual-level sequence and relevant phenotypic data are approved by the NIH to be shared through Kids First Data Resources
- Samples that are consented in a way that allows broad access and use, including combining and cross-analyzing datasets (General Research Use, Health/Medical/Biomedical), will be prioritized

Institutional Certification Required

1) Download the current NIH Institutional (or Provisional) Certification template: https://osp.od.nih.gov/scientific-sharing/institutional-certifications/

2) Fill out the first page, include all sites contributing samples for sequencing.

3) Provide the Institutional Certification to the IRB (or equivalent) along with the participant consent forms for each site and any other pertinent information.

4) The IRB reviews the consent form(s) to determine the data use limitations (DULs) and/or DUL modifiers for each consent form.

   - **"General Research Use" with no modifiers is expected for individual-level data**, unless specific uses are clearly prohibited in the participant consent
   - **"Unrestricted" access is expected for genomic summary results** unless a justification is provided for designating the dataset as "sensitive"

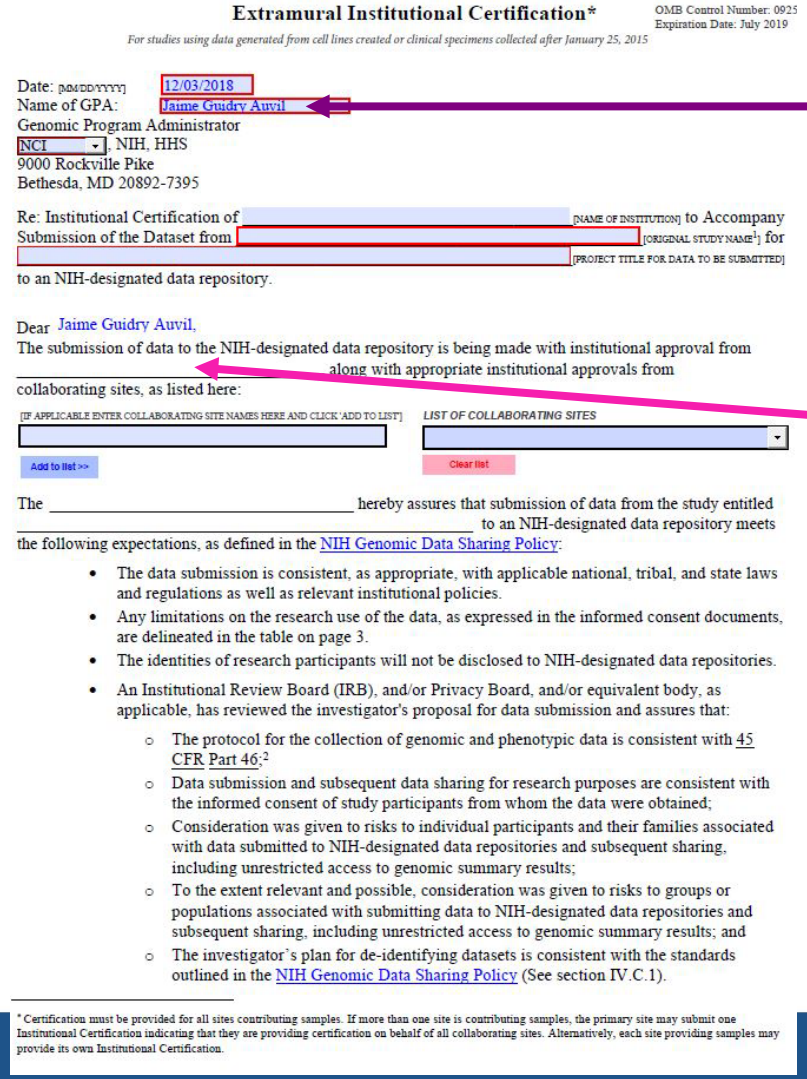
5) After IRB review, the Institutional Certification is signed by the appropriate officials and submitted to NIH.

Institutional Certification: Page 1

Step by step tips:

1) Name of GPA: Valerie Cotton, NICHD

2) List all sites contributing samples



Extramural Institutional Certification*

OMB Control Number: 0925
Expiration Date: July 2019

For studies using data generated from cell lines created or clinical specimens collected after January 25, 2015

Date: [MM/DD/YYYY] 12/03/2018
Name of GPA: Jaime Guidry Auvil
Genomic Program Administrator
NCI, NIH, HHS
9000 Rockville Pike
Bethesda, MD 20892-7395

Re: Institutional Certification of [NAME OF INSTITUTION] to Accompany Submission of the Dataset from [ORIGINAL STUDY NAME[1]] for [PROJECT TITLE FOR DATA TO BE SUBMITTED] to an NIH-designated data repository.

Dear Jaime Guidry Auvil,

The submission of data to the NIH-designated data repository is being made with institutional approval from _____ along with appropriate institutional approvals from collaborating sites, as listed here:

[IF APPLICABLE ENTER COLLABORATING SITE NAMES HERE AND CLICK 'ADD TO LIST'] | LIST OF COLLABORATING SITES

Add to list >> | Clear list

The _____ hereby assures that submission of data from the study entitled _____ to an NIH-designated data repository meets the following expectations, as defined in the NIH Genomic Data Sharing Policy:

- The data submission is consistent, as appropriate, with applicable national, tribal, and state laws and regulations as well as relevant institutional policies.
- Any limitations on the research use of the data, as expressed in the informed consent documents, are delineated in the table on page 3.
- The identities of research participants will not be disclosed to NIH-designated data repositories.
- An Institutional Review Board (IRB), and/or Privacy Board, and/or equivalent body, as applicable, has reviewed the investigator's proposal for data submission and assures that:
  - The protocol for the collection of genomic and phenotypic data is consistent with 45 CFR Part 46;[2]
  - Data submission and subsequent data sharing for research purposes are consistent with the informed consent of study participants from whom the data were obtained;
  - Consideration was given to risks to individual participants and their families associated with data submitted to NIH-designated data repositories and subsequent sharing, including unrestricted access to genomic summary results;
  - To the extent relevant and possible, consideration was given to risks to groups or populations associated with submitting data to NIH-designated data repositories and subsequent sharing, including unrestricted access to genomic summary results; and
  - The investigator's plan for de-identifying datasets is consistent with the standards outlined in the NIH Genomic Data Sharing Policy (See section IV.C.1).

* Certification must be provided for all sites contributing samples. If more than one site is contributing samples, the primary site may submit one Institutional Certification indicating that they are providing certification on behalf of all collaborating sites. Alternatively, each site providing samples may provide its own Institutional Certification.

GPA: Valerie Cotton, NICHD

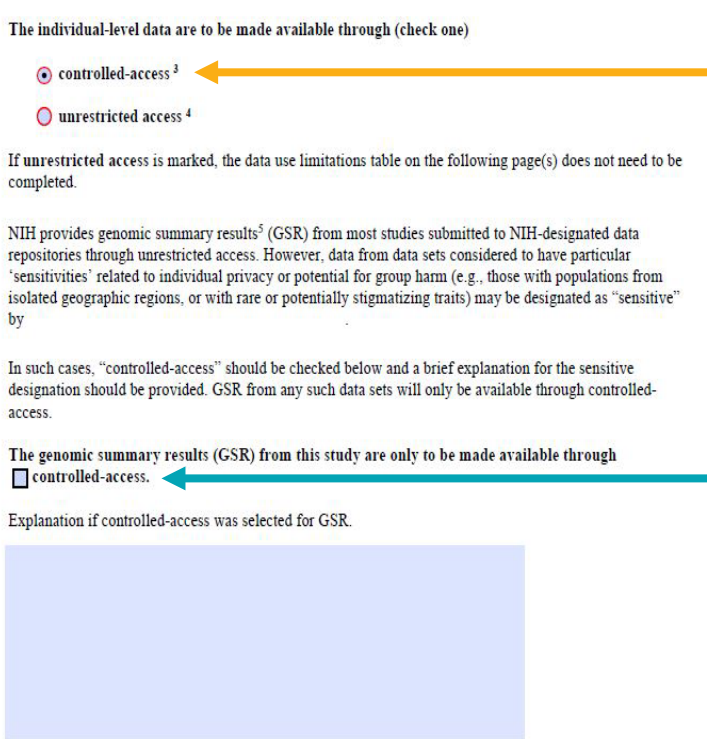
List all sites contributing samples

Institutional Certification: Page 2

Step by Step Tips:

1) Under **"The individual-level data are to be made available through (check One)"** – It is expected to check the box **"controlled-access"**

2) Under **"The genomic summary results (GSR) from this study are only to be available through"** – It is expected to be keep the box "**controlled access**" unchecked.


The individual-level data are to be made available through (check one)

controlled-access [3]

unrestricted access [4]

If unrestricted access is marked, the data use limitations table on the following page(s) does not need to be completed.

NIH provides genomic summary results[5] (GSR) from most studies submitted to NIH-designated data repositories through unrestricted access. However, data from data sets considered to have particular 'sensitivities' related to individual privacy or potential for group harm (e.g., those with populations from isolated geographic regions, or with rare or potentially stigmatizing traits) may be designated as "sensitive" by

In such cases, "controlled-access" should be checked below and a brief explanation for the sensitive designation should be provided. GSR from any such data sets will only be available through controlled-access.

The genomic summary results (GSR) from this study are only to be made available through

controlled-access.

Explanation if controlled-access was selected for GSR.

individual-level sequence data are expected to be "controlled-access", unless consent allows for unrestricted access

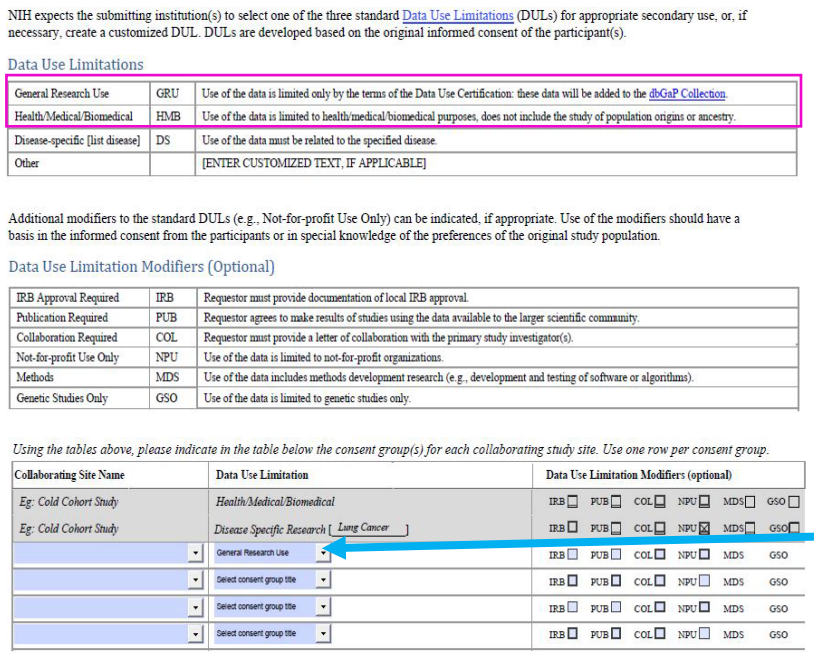
Keep unchecked for "unrestricted" access to **genomic summary results** unless the IRB provides a justification for designating the dataset as "sensitive"

Institutional Certification: Page 3

Step by step tips:

1) Datasets that are consented for General Research Use **(GRU)** and/or Health/Medical/Biomedical **(HMB)** purposes will be prioritized over datasets restricted to Disease Specific use.

2) **No modifiers** is expected.



NIH expects the submitting institution(s) to select one of the three standard Data Use Limitations (DULs) for appropriate secondary use, or, if necessary, create a customized DUL. DULs are developed based on the original informed consent of the participant(s).

Data Use Limitations

General Research Use	GRU	Use of the data is limited only by the terms of the Data Use Certification: these data will be added to the dbGaP Collection.
Health/Medical/Biomedical	HMB	Use of the data is limited to health/medical/biomedical purposes, does not include the study of population origins or ancestry.
Disease-specific [list disease]	DS	Use of the data must be related to the specified disease.
Other		[ENTER CUSTOMIZED TEXT, IF APPLICABLE]

Additional modifiers to the standard DULs (e.g., Not-for-profit Use Only) can be indicated, if appropriate. Use of the modifiers should have a basis in the informed consent from the participants or in special knowledge of the preferences of the original study population.

Data Use Limitation Modifiers (Optional)

IRB Approval Required	IRB	Requestor must provide documentation of local IRB approval.
Publication Required	PUB	Requestor agrees to make results of studies using the data available to the larger scientific community.
Collaboration Required	COL	Requestor must provide a letter of collaboration with the primary study investigator(s).
Not-for-profit Use Only	NPU	Use of the data is limited to not-for-profit organizations.
Methods	MDS	Use of the data includes methods development research (e.g., development and testing of software or algorithms).
Genetic Studies Only	GSO	Use of the data is limited to genetic studies only.

Using the tables above, please indicate in the table below the consent group(s) for each collaborating study site. Use one row per consent group.

Collaborating Site Name	Data Use Limitation	Data Use Limitation Modifiers (optional)
Eg: Cold Cohort Study	*Health/Medical/Biomedical*	IRB ☐ PUB ☐ COL ☐ NPU ☐ MDS ☐ GSO ☐
Eg: Cold Cohort Study	*Disease Specific Research [Lung Cancer]*	IRB ☐ PUB ☐ COL ☐ NPU ☒ MDS ☐ GSO ☐
	General Research Use	IRB ☐ PUB ☐ COL ☐ NPU ☐ MDS GSO
	Select consent group title	IRB ☐ PUB ☐ COL ☐ NPU ☐ MDS GSO
	Select consent group title	IRB ☐ PUB ☐ COL ☐ NPU ☐ MDS GSO
	Select consent group title	IRB ☐ PUB ☐ COL ☐ NPU ☐ MDS GSO

"General Research Use" with no modifiers is expected for individual-level data, unless specific uses are clearly prohibited

Provisional Certification: Fillable Table

Step by step tips:

1) It is acceptable to submit a provisional certification if a full certification is not ready by the application deadline.

1) Provisional Certification: Data Sharing and Data Use Limitations

If you provided a Provisional Institutional Certification, because you are unable to provide a full Institutional Certification, please describe the anticipated data use limitations based on the language of the consent form(s) signed by the participants in the proposed cohort. For a list of standard DULs and modifiers, please review the Institutional Certification template: https://osp.od.nih.gov/scientific-sharing/institutional-certifications or https://osp.od.nih.gov/wp-content/uploads/standard_data_use_limitations.pdf.

Site	**Data Use Limitation** (GRU, HMB, DS)	**Data Use Limitation Modifiers** (IRB, PUB, COL, NPU, MDS, GSO)

Examples of Data Use Limitations and Modifiers Limit Broad Data Sharing

- **Disease Specific Consent Group:**
  - When data use is restricted to a specific disease area, the data cannot be combined with a dataset with a different disease specific data use limitation.
- **IRB modifier:**
  - With this box checked, the Requester must provide documentation of a their local IRB's approval for the proposed research. We find that it is rare for consent language to include such a requirement and that this modifier is often included in error.
- **COL modifier:**
  - This box is checked when the consent form states that collaboration with the original/submitting investigator is required in order to use the dataset; therefore, the Requestor must provide a collaboration agreement document in order to be approved for access the dataset. This can limit the number of end-users who are able to use the dataset.

For more detail on DUL definitions:
https://osp.od.nih.gov/wp-content/uploads/NIH_PTC_in_Developing_DUL_Statements.pdf

Data Use Certification (DUC)

- As a reminder, every requester and their institution must agree to the terms of the Data Use Certification (DUC), which verifies that the requesting PI is accredited within the institution, the institution is aware of the project for which the PI is proposing to use the data, and that the Institution has all appropriate security measures in place to manage and maintain the controlled-access dataset(s) being retrieved.

Clinical & Phenotypic Data

Goal:

- Well annotated data empowers analyses and informs how pathways/conditions overlap. The KF Data Resource Center will leverage existing community standards to harmonize clinical/phenotypic data which facilitates searching, analysis, and interoperability with other data efforts.

Expectations:

- Basic data elements and deep phenotyping is preferred.
- Describe what clinical/phenotypic information is available and how these data will:
    1) support your proposed analysis
    2) enhance research through the Kids First Resources

Clinical/Phenotypic Data & Demographics: Fillable Table

Step by step tips:

1) Proposals with rich information about phenotypes and clinical data will be prioritized over projects with limited information.

Available Phenotype or Clinical Information (for #3 Clinical, Phenotypic, and Demographic Data). Please edit or add to the table below to indicate what phenotype information is available for the case/proband, parents, and/or other family members. The information you list is intended to be shared through the Kids First Data Resource.

Demographics	Case/Proband/Affected	Unaffected family members/parents
o Age at enrollment or age at diagnosis		
o Other age information (age at specimen collection, age at death etc.…)		
o Sex		
o Race		
o Hispanic ethnicity		
o List any other demographic information:		

Clinical information (e.g., diagnoses, type of birth defect, primary tumor type, vital status, age at last know vital status, treatment information).		
	Case/Proband/Affected	Unaffected family members/parents
List the variables:		
Are electronic health records available?		

Other phenotypic information (e.g., other phenotypic measurements that may be related to the primary outcome)		
	Case/Proband/Affected	Unaffected family members/parents
List the variables		

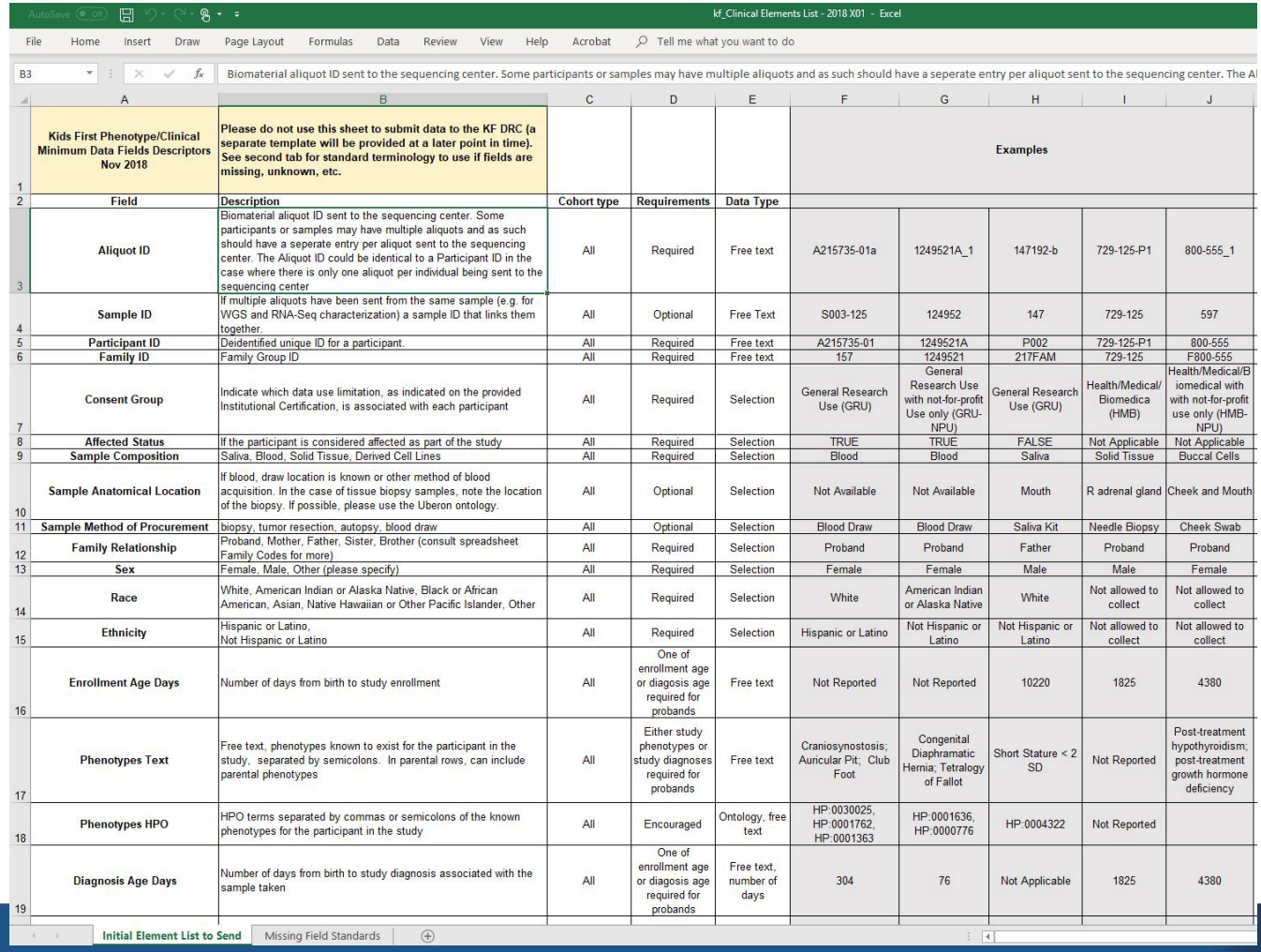
Family medical history (e.g., family history of birth defects, family history of cancer)		
	Case/Proband/Affected	Unaffected family members/parents
List the variables:		

Biospecimen & Phenotypic Data Elements

Step by step tips:

1) Projects must provide minimum descriptors of cohorts

2) Data elements tailored to your cohort is encouraged.



kf_Clinical Elements List - 2018 X01 - Excel

File Home Insert Draw Page Layout Formulas Data Review View Help Acrobat Tell me what you want to do

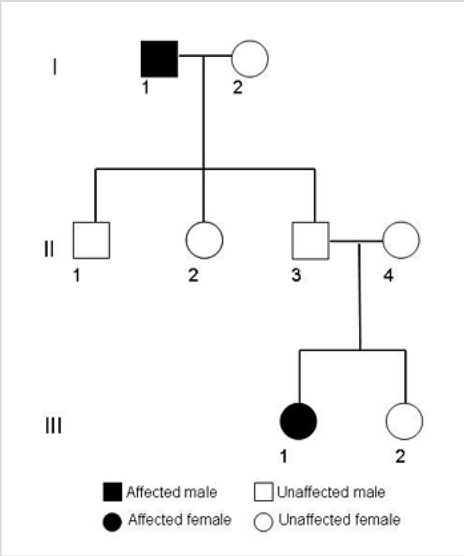
B3: Biomaterial aliquot ID sent to the sequencing center. Some participants or samples may have multiple aliquots and as such should have a seperate entry per aliquot sent to the sequencing center. The Al

	A	B	C	D	E	F	G	H	I	J
1	Kids First Phenotype/Clinical Minimum Data Fields Descriptors Nov 2018	Please do not use this sheet to submit data to the KF DRC (a separate template will be provided at a later point in time). See second tab for standard terminology to use if fields are missing, unknown, etc.				Examples				
2	Field	Description	Cohort type	Requirements	Data Type					
3	Aliquot ID	Biomaterial aliquot ID sent to the sequencing center. Some participants or samples may have multiple aliquots and as such should have a seperate entry per aliquot sent to the sequencing center. The Aliquot ID could be identical to a Participant ID in the case where there is only one aliquot per individual being sent to the sequencing center	All	Required	Free text	A215735-01a	1249521A_1	147192-b	729-125-P1	800-555_1
4	Sample ID	If multiple aliquots have been sent from the same sample (e.g. for WGS and RNA-Seq characterization) a sample ID that links them together.	All	Optional	Free Text	S003-125	124952	147	729-125	597
5	Participant ID	Deidentified unique ID for a participant.	All	Required	Free text	A215735-01	1249521A	P002	729-125-P1	800-555
6	Family ID	Family Group ID	All	Required	Free text	157	1249521	217FAM	729-125	F800-555
7	Consent Group	Indicate which data use limitation, as indicated on the provided Institutional Certification, is associated with each participant	All	Required	Selection	General Research Use (GRU)	General Research Use with not-for-profit Use only (GRU-NPU)	General Research Use (GRU)	Health/Medical/ Biomedica (HMB)	Health/Medical/Biomedical with with not-for-profit use only (HMB-NPU)
8	Affected Status	If the participant is considered affected as part of the study	All	Required	Selection	TRUE	TRUE	FALSE	Not Applicable	Not Applicable
9	Sample Composition	Saliva, Blood, Solid Tissue, Derived Cell Lines	All	Required	Selection	Blood	Blood	Saliva	Solid Tissue	Buccal Cells
10	Sample Anatomical Location	If blood, draw location is known or other method of blood acquisition. In the case of tissue biopsy samples, note the location of the biopsy. If possible, please use the Uberon ontology.	All	Optional	Selection	Not Available	Not Available	Mouth	R adrenal gland	Cheek and Mouth
11	Sample Method of Procurement	biopsy, tumor resection, autopsy, blood draw	All	Optional	Selection	Blood Draw	Blood Draw	Saliva Kit	Needle Biopsy	Cheek Swab
12	Family Relationship	Proband, Mother, Father, Sister, Brother (consult spreadsheet Family Codes for more)	All	Required	Selection	Proband	Proband	Father	Proband	Proband
13	Sex	Female, Male, Other (please specify)	All	Required	Selection	Female	Female	Male	Male	Female
14	Race	White, American Indian or Alaska Native, Black or African American, Asian, Native Hawaiian or Other Pacific Islander, Other	All	Required	Selection	White	American Indian or Alaska Native	White	Not allowed to collect	Not allowed to collect
15	Ethnicity	Hispanic or Latino, Not Hispanic or Latino	All	Required	Selection	Hispanic or Latino	Not Hispanic or Latino	Not Hispanic or Latino	Not allowed to collect	Not allowed to collect
16	Enrollment Age Days	Number of days from birth to study enrollment	All	One of enrollment age or diagosis age required for probands	Free text	Not Reported	Not Reported	10220	1825	4380
17	Phenotypes Text	Free text, phenotypes known to exist for the participant in the study, separated by semicolons. In parental rows, can include parental phenotypes	All	Either study phenotypes or study diagnoses required for probands	Free text	Craniosynostosis; Auricular Pit; Club Foot	Congenital Diaphramatic Hernia; Tetralogy of Fallot	Short Stature < 2 SD	Not Reported	Post-treatment hypothyroidism; post-treatment growth hormone deficiency
18	Phenotypes HPO	HPO terms separated by commas or semicolons of the known phenotypes for the participant in the study	All	Encouraged	Ontology, free text	HP:0030025, HP:0001762, HP:0001363	HP:0001636, HP:0000776	HP:0004322	Not Reported	
19	Diagnosis Age Days	Number of days from birth to study diagnosis associated with the sample taken	All	One of enrollment age or diagosis age required for probands	Free text, number of days	304	76	Not Applicable	1825	4380

Initial Element List to Send | Missing Field Standards

Pedigree or Table

- Describe Family structures (proband-parent dyads, proband-parent-sibling quads, multiplex families, consanguineous families).
- How many samples per family? How many are affected/unaffected?



Family type	Number of families	Total Germline Samples
Proband/Child + Parents (unaffected) Trios	XX	XX affected XX unaffected
Proband + 1 affected FDR + [Unaffected FDRs]	XX	XX affected XX unaffected
Proband + 2 affected FDR + [Unaffected FDRs]	XX	XX affected XX unaffected
Total	XXX	XXX

FDR= First Degree Relative

Examples of Research Projects

- Discovery of biology, and genetic variants underlying their targeted disorder using various study designs (e.g., trio-based, family-based, or other)
- Germline whole genome sequencing (WGS) -standard short-read whole genome sequencing
- Long-read sequencing approaches.
- Integrative -omics approach. For example, transcriptomic (RNAseq), epigenomic (e.g., genome-wide methylation, chromatin accessibility, and proteomics data generation for tumors and/or affected tissue.
- Increase diversity within our datasets and to improve coverage of underrepresented populations (e.g. Blacks or African Americans, Hispanics or Latinos, American Indians or Alaska Natives, Native Hawaiians and other Pacific Islanders)
- Represent conditions not previously sequenced by Kids First (if many applications score well and meet other criteria)
- Additional or alternative approaches may be proposed

Project design will be finalized in collaboration with X01 investigators, the sequencing centers, Kids First Data Resource Center, and NIH program staff.

Take Home Messages

- Read and follow guidance from the program announcement!
  - X01 gives access to generate genomic data performed at designated Kids First Sequencing Centers
  - X01 does not fund data analysis but projects showing a strong data analysis plan are prioritized
- Program prioritizes proposals with inclusive and diverse cohorts bringing rich phenotypic and clinical information and allowing broad data sharing
  - Data use does not require approval by an Institutional Review Board for secondary analyses
  - Data have no publication embargo
- Selected projects are not listed in the NIH RePORTER
  - Abstracts and X01 information listed on Kids First website. https://commonfund.nih.gov/kidsfirst/fundedresearch

Data is made accessible through dbGaP & the Kids First Data Resource

- All Kids First projects are registered, authenticated, and approved through dbGaP.
- All dbGaP Data Access Requests will be processed by **the Kids First Data Access Committee** run by the NCI Office of Data Sharing.
- Kids First Data Resource is the NIH designated repository for Kids First data.

Kids First Data Access Committee (NIH)

Kids First Cloud-Based Resources

Platforms

Kids First Data Resource Portal

EXPLORE datasets and build cohorts of participants

DISCOVER harmonized genomic data files for further research

CONNECT data from multiple Kids First studies

CAVATICA

COMPUTE large scale workflows on genomic data files

ANALYZE data in the cloud via R Studio and Python Notebooks. Bring your own or use available notebooks.

SHARE tasks and findings with collaborators around the world, pull data from multiple sources into one workplace

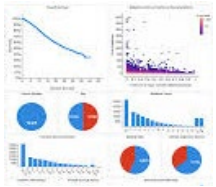
Tools and Framework

Data Resource Portal

Entry point. Query, search, discover, build & visualize synthetic cohorts

Knowledge Base Integrations (PedcBioPortal)

Integrations with existing curated/published data visualizations



Data Services

Exchange clinical data in FHIR-based data services for semantic interoperability and coordination

Framework Services

Index and point to files in the cloud (for approved users)

Cloud- credits

Data analysis

It takes a Village

Children's Hospital of Philadelphia

CHU Sainte-Justine Research Center
Mother and Child University Hospital Center

VELSERA

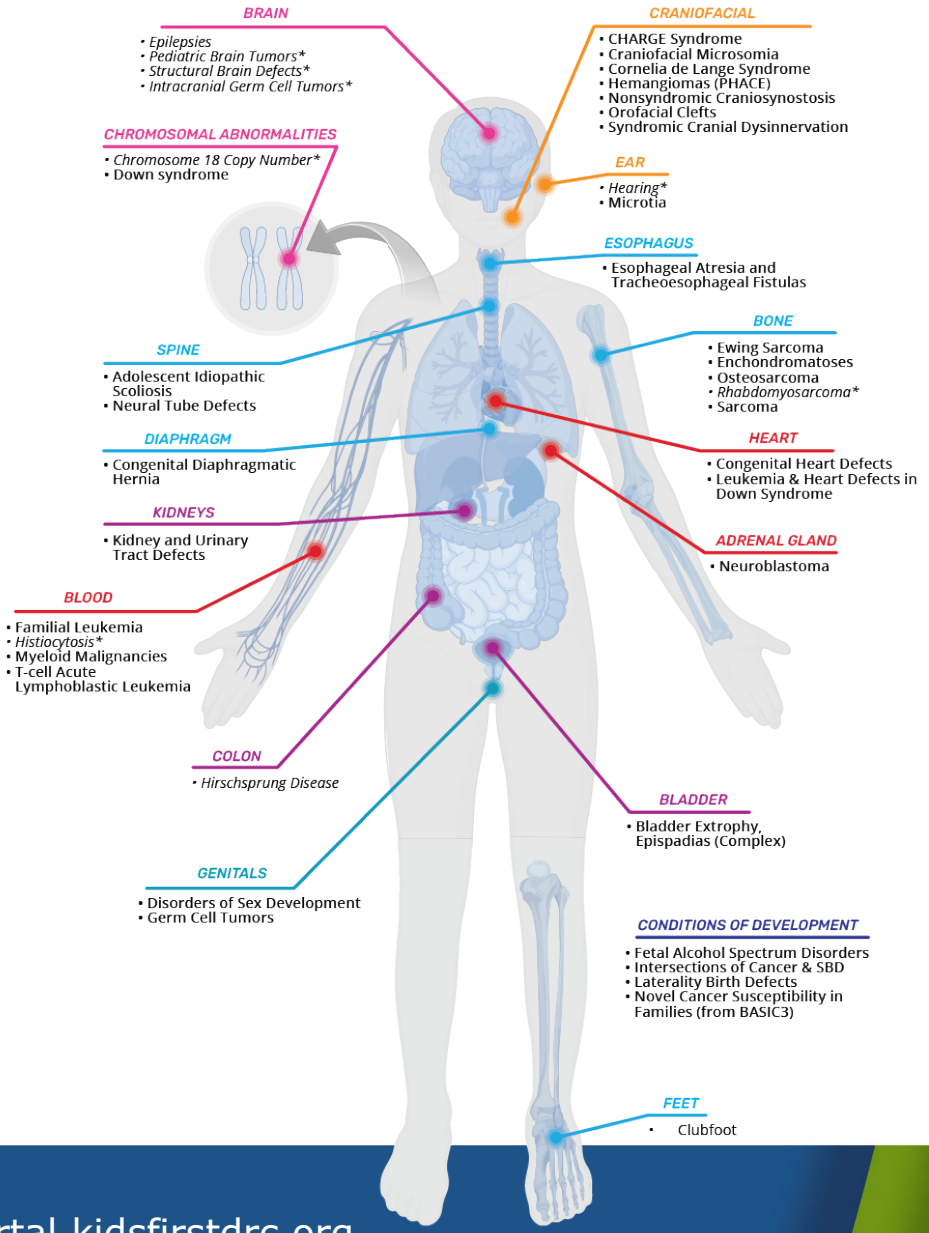
The University of Chicago

University of Colorado Anschutz Medical Campus

Vanderbilt University

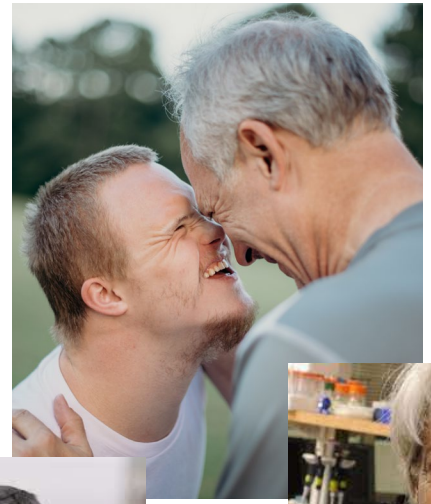
Kids First Data Available

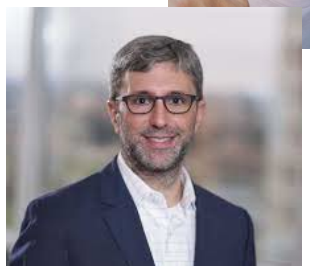
- **33** new pediatric cohorts released to date
- **27,000+** genomes available from affected children and families
- **620+** approved data access requests for secondary use
- **Data publicly available** via dbGaP



Kids First Collaborations for Data Release Across Pediatric Conditions

- July 10, 2023 "Kids First and INCLUDE: Down Syndrome, Heart Defects, and Acute Lymphoblastic Leukemia".
- Children with Down Syndrome (DS) have a 2000-fold increased risk of atrioventricular septal defects (AVSD) and a 20-fold increased risk of acute lymphoblastic leukemia (ALL).
- The objectives of this study are to determine the genetic variants underlying AVSD and ALL risk in children with Down Syndrome. WGS data for children with DS-AVSD was compared to data from children with DS who have structurally normal hearts. WGS data for children with DS-ALL was compared with children with DS without history of ALL.
- Data available from 2489 participants along with phenotypes and clinical information





Philip Lupo
Baylor College of Medicine
Houston, TX, USA

Stephanie Sherman
Emory University
Atlanta, GA, USA

Kids First Data Resource Portal Metrics

ABOUT THE DATA

22
Birth defect cohorts

11
Cancer cohorts

27,000+
Study participants

192,000+
Data files available

ABOUT THE PORTAL

50
Unique countries represented by portal users

650+
Approved access requests for secondary data use

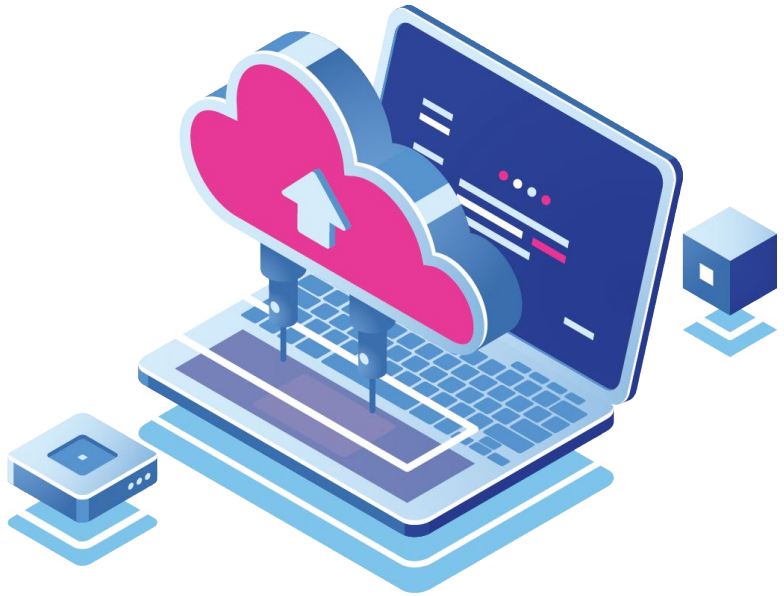
3,389+
Total portal users

6,500+
Total portal logins in 2022

Kids First Genetic Variant Browser

Kids First Cloud Credits Pilot

- Sponsored by NIH
- Must apply a Kids First dataset and CAVATICA
  - 18 projects approved to date
    - 10 structural birth defects
    - 8 childhood cancers
- Average of duration of projects 4-15 months
- Opportunity to follow-up with more credits
  - 3 projects approved for additional credits
- Apply via Email - How to Apply
- More information - Github

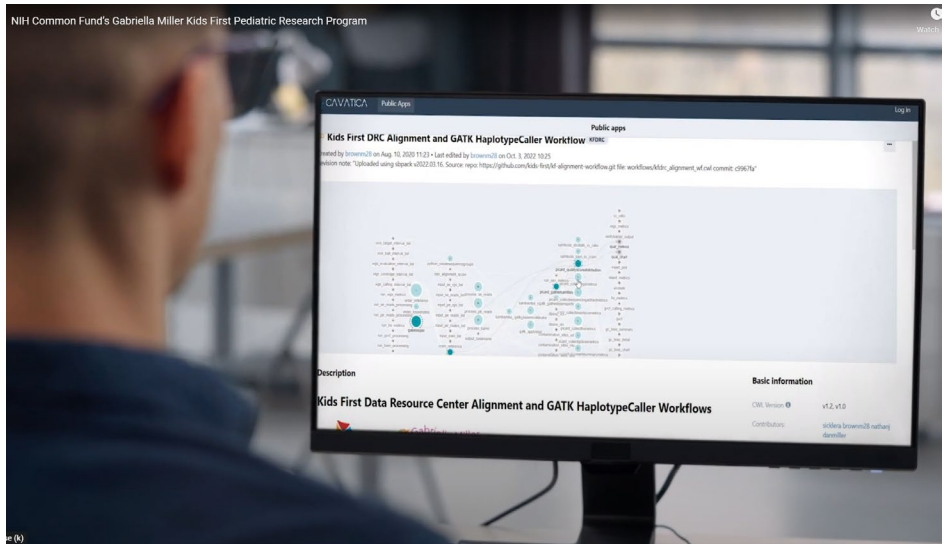


IC sponsored R03 for KF data analysis

[Small Research Grants for Analyses of Gabriella Miller Kids First Pediatric Research Data (R03 Clinical Trial Not Allowed)](#) (PAR-23-075)

The NIH Common Fund has established the Gabriella Miller Kids First Pediatric Research Program (Kids First) to develop a pediatric research data resource populated by genome sequence and phenotypic data that will be of high value for the communities of investigators who study the genetics of childhood cancers and/or structural birth defects.

Important Date: Various



Short Courses

Short Courses to Promote the Broad and Rigorous Use of Common Fund Data (R25 Clinical Trial Not Allowed) (nih.gov) (RFA-RM-23-014)

The NIH Research Education Program (R25) is dedicated to fostering research education within biomedical, behavioral, and clinical research needs.

Training Courses:
•Enhance workforce training through various educational activities.
•Encourage the use of multiple Common Fund datasets in rigorous biomedical studies through short training schemes.

Diversity & Inclusion:
•Strive for the inclusion of diverse communities by promoting their retention among Common Fund data users.
•Providing professional mentoring crucial for community inclusion.

Application Receipt Date: February 14, 2024

Kids First X01 FY2024

Discovery of the Genetic Basis of Childhood Cancers and of Structural Birth Defects: Gabriella Miller Kids First Pediatric Research Program (X01 Clinical Trial Not Allowed) (PAR-24-082)

As part of the Gabriella Miller Kids First Pediatric Research Program (Kids First Program), the NIH invites applications to submit samples from pediatric cohorts for whole genome sequencing at a Kids First Program supported sequencing centers.

Application Receipt Date(s): March 13, 2024

Genomic Data Sharing Contacts

Marcia Fournier
Program Manager
KidsFirst@od.nih.gov

Valerie Cotton
Genomic Program Administrator (GPA)
Deputy Director of Data Science and Sharing NICHD

Jaime M. Guidry Auvil, Ph.D.
Director, NCI Office of Data Sharing
NCIOfficeofDataSharing@mail.nih.gov

General NIH Genomic Data Sharing
GDS@mail.nih.gov

Q&A

- Use the “chat” to ask questions.
- After the webinar, additional questions can be emailed to: KidsFirst@od.nih.gov.