Informed Consent Form and HIPAA Authorization

Study Title: Clinical and Molecular Studies of Growth and Epigenetic Alterations

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You, or your child, may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of this research study and the risks and possible benefits of participating.

If there is anything in this consent form you do not understand, please ask questions. Please take your time. You do not have to take part in this study if you do not want to. If you take part in this study, you can leave the study at any time.

In the sections that follow, the word "we" means the study doctor and other research staff. If you are a parent or legal guardian who is giving permission for a child, please note that the word "you" refers to your child.

Why are you being asked to take part in this study?

You are being asked to take part in this research study because you are either a:

- Patient who has a proven or suspected growth or epigenetic difference; or a
- Family member including but not limited to parent or sibling of a patient with a proven or suspected growth or epigenetic difference.

What is the purpose of this research study?

The purpose of this research is to look how your genes influence how your body grows. We will collect information and samples from people with differences in growth and their family members.

- A collection of samples (specimens) and information (data) is called a biorepository.
- The samples and information will be used for future research that will involve various types of genetic testing.
- Genetic testing looks at pieces of DNA called genes. Genes provide the instructions needed to make our bodies work. We will try to find regions of the DNA that might be responsible for growth. We will also look at other factors associated with those genes (proteins, RNA).

We hope that the information and samples in the biorepository will help us find the causes and better treatments for conditions and diseases, which influence growth in children.

What is involved in the study?

The study will look at your medical history and medical exam and collect samples from you. We will save this information so we can study it in the future. The medical history and exam information will be kept in a *registry* and the samples will be kept in a *biorepository*.

How long will you be in this study?

If you agree to take part in the study, you will be in this study for as long as you let us follow you. The study involves 1 study visit at CHOP for CHOP patients and looking at your medical records and a phone conversation for patients not cared for at CHOP. This may be done as part of a clinic visit or may be a separate visit lasting 15-30 minutes. We will continue to update the information from your medical record for as long as you allow us.

If you are not a patient at CHOP, we will ask you to sign a separate form to allow us to look at your medical records. We will also collect leftover samples. This may require some of your time or your doctor's time to help organize collecting your medical records and samples.

The samples and information that we collect for the biorepository and registry, respectively, will be stored for future studies.

What are the study procedures?

The study involves the following:

Medical History: Information (data) will be collected from your medical records (patients) or from a brief interview (relatives). We will collect information such as diagnosis, treatments, and outcome. If you are cared for at CHOP, your data will be updated every 6 months until you turn 18 years of age. After you turn 18, we will contact you and request that you continue to allow us to update your information. You will have to sign another form like this if you agree to stay in the study once you turn 18 years of age. If you are not a CHOP patient, you will be asked to sign a medical release form and your data will be updated every 6 months through a phone conversation and sharing of updated records from your physician.

Physical Exam: A physical exam may be performed which could range from a full physical exam to a focused exam on one region of the body. If you are a CHOP patient, this may be part of your routine medical care. Family members may have a focused exam.

Blood Samples: We may collect tube(s) of blood from you. An approximate amount of 3-15mL of blood is anticipated, however the exact amount collected will depend upon your size and the amount of other collections performed at the same time, as applicable.

If you are a CHOP patient, the sample will be collected when you are having blood drawn for your medical care. A separate blood draw may need to be done if we cannot coordinate the collection of the research sample with a clinical blood draw for your medical care.

If you are a family member of a patient, you will be asked for a blood sample, which will be collected at the time of your child or relative's clinic visit by Dr. Kalish or a credentialed study team member. This blood sample can also be collected as a left over sample when you have blood drawn for your medical care. Please note that this blood sample is not required in order for patients to be in the study; your child/family member can still be in this study even if you do not give a blood sample. Please note, relatives and CHOP patient/subjects will need to sign separate consent forms.

Skin Biopsy: Some genes cannot be studied well from blood cells but can be studied in skin cells. If based on the medical history and/or physical exam of you or your family member, we expect the genetic change occurred in skin, we may ask you (as a patient or family member of a patient) to have a skin biopsy performed. This requires the use of a local anesthetic to numb the skin, and a 3mm round small biopsy to be obtained. You do not have to have a skin biopsy to participate in this study.

Tissue Specimens: Any tissue or body fluid that is removed during a medical or surgical procedure (such as skin, muscle, bone, fat) and is not needed for medical care may be obtained from the clinical lab or pathology to be stored in the biorepository. Often, this leftover tissue would be thrown away.

Other Specimens: We will also request the following: a urine sample, which would require peeing into a cup or collection bag, a saliva sample, which would require spitting some saliva into a small cup, or a cheek cell sample, which involves rubbing several brushes on the inside of the cheek for about 10 seconds.

If samples are collected or stored at CHOP, samples will be collected from their storage at CHOP. If samples or medical information are not collected or stored at CHOP, the investigators will work with you and/or your physician to collect/retrieve the information or samples and have them sent to CHOP without charge to you or your physician. We will ask you to sign a release of information form so we can arrange for these samples to be sent to us.

Photography: Photographs and audiovisual recordings may be taken as part of this study. This may include photographs, which can identify you, such as pictures of your face.

Questionnaire: You will have the opportunity to indicate your choices for returning research results in a questionnaire.

How will my data and samples be protected?

The data and samples will first have all information that identifies you (such as your name) removed. Your identifying information will be replaced by a unique code number. This information will be kept in a separate file (key) that links your code number to your

identifiable information. This key is necessary since your medical data may be updated in the future. The key will NOT be stored in the biorepository.

When your data and samples are stored in the registry and biorepository, they will only have the unique code number. None of the researchers who will use materials in the biorepository for future studies will have the key to the code. The person who removes the identifiers will not be allowed to share the key with anyone else.

What will be done with my data and samples?

- Samples will be used to create cell lines that will be used to study growth.
- Clinical information will be studied to determine whether any genetic, epigenetic or clinical features are better predictors of tumors than methods that are currently used.
- A variety of different tests may be done on your samples, including genetic tests. Because the field of genetic testing is advancing rapidly, we cannot predict all of the tests that will be done.

Could I be re-identified in the future?

One of the goals of this registry is to help connect patients with clinicians and researchers trying to understand clinical questions and treatments. At the end of this form, please indicate whether or not you agree to be contacted for future studies. If you agree to be contacted about future studies, one of the investigators from this study will contact you when a researcher has a study to offer and you can decide if you are interested in that new study. If you are interested, you will have the choice to contact or be contacted for that other study.

What are the risks of this study?

Taking part in a research study involves inconveniences and risks. If you have any questions about any of the possible risks listed below, you should talk to your study doctor or your regular doctor.

Risks associated with genetic testing:

The risks related to genetic testing can be to individuals or groups. These harms include stigmatization and insurability. To reduce this risk, only coded samples will be stored and used for future research. Information about this study will not be recorded in your medical record.

The Genetic Information Nondiscrimination Act is a Federal law that makes it illegal for some groups to discriminate against you based on genetic information. This law applies to all health insurance companies, group health plans, and employers with 15 or more employees. This law does not apply to companies that sell life insurance, disability insurance, or long-term care insurance.

Because genes include many types of information, in addition to identifying causes that may be related to growth, we may also find information that we were not looking for, called “incidental findings.” Many genetic tests are experimental, and the meaning of the test results is not known.

- If the research tests find anything that suggests a possible clinically significant finding or might explain a known clinical problem for you, we will refer you to have clinical testing. Only if the clinical test confirms the research test results is the finding valid. This testing will take place outside of this research study.

None of the research findings can be considered validated and therefore will not be shared with your doctors, third parties, or family members.

Risks associated with collection of blood:

Taking blood may cause some pain, bleeding or bruising at the spot where the needle enters your body. Rarely, taking blood may cause fainting or infection.

If possible, the research blood sample(s) will be collected at the same time you have blood drawn for medical care or through an existing catheter already inserted into a vein.

Risks associated with a skin biopsy:

Sometimes a skin biopsy may cause minor bleeding, which is minimized by using medicine to try and stop the bleeding and holding pressure following the biopsy. There can be some pain and/or soreness. We will give you medicine (local cream or injected anesthetic) if needed. There is a small risk of infection. We will keep the biopsy site clean and use antibiotic cream. A small scar can form where the biopsy was taken. We will give you an information sheet on how to care for the skin biopsy site at home.

Risks associated with collection of urine, saliva and cheek cell samples:

The physical risks of these procedures are all minimal. A cheek swab could cause irritation in the cheek where the swab was taken.

Risks associated with collection of leftover tissue:

Only tissue that is leftover from a clinical procedure and that would normally be thrown away will be used for the research. There are no additional risks from the collection of these samples.

Risks to your personal privacy and confidentiality:

This research uses medical information and includes genetic testing. Your participation in this research will be kept strictly confidential (private). Only a unique code number will be used with your samples and information. However, there will be a link between your unique code number and your name. This link means that your privacy cannot always be guaranteed.

Are there any benefits to taking part in this study?

Being in this study will not benefit you directly. We hope that this study will help scientists and doctors understand genetic diseases. The study may also help researchers find better ways to diagnose and treat genetic diseases in the future.

Do you need to give your consent in order to participate?

If you decide to participate in this study, you must sign this consent form. A copy will be given to you to keep as a record. Please consider the time needed and responsibilities to

be in the study as a research subject when making your decision about participating in this study.

What happens if you decide not to take part in this study?

Participation in this study is voluntary. You do not have to take part in order to receive care at CHOP.

If you decide not to take part or if you change your mind later there will be no penalties or loss of any benefits to which you are otherwise entitled.

Can you stop your participation in the study early?

You can stop being in the study at any time. You do not have to give a reason.

What about privacy, authorization for use of Personal Health Information (PHI) and confidentiality?

As part of this research, health information about you will be collected. This will include information from your medical records and samples. Information related to your medical care at CHOP will go in your medical record. This could include physical exams, imaging studies (x-rays or MRI scans) or tests done in the clinical lab. Medical records are available to CHOP staff. Staff will view your records only when required as part of their job. Staff are required to keep your information private. Information that could identify you will not be shared with anyone - unless you provide your written consent, or it is required or allowed by law. No research laboratory test results will appear in your medical records. We will do our best to keep your personal information private and confidential. However, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law.

The results of this study may be shown at meetings and published in journals to teach other doctors and health professionals. We will keep your identity private in any publication or presentation, unless you explicitly give us consent for publication of facial photographs, which will be shown without your name or other identifying information.

Several people and organizations may review or receive your identifiable information. They will need this information to conduct the research, to assure the quality of the data, or to analyze the data or samples. These groups include:

- Members of the research team and other authorized staff at CHOP;
- People from agencies and organizations that perform independent accreditation and/or oversight of research, such as the Department of Health and Human Services or Office for Human Research Protections;
- Your samples/data may be shared with University of Pennsylvania laboratories and/or other laboratories involved in genetic diagnostics, genetics, cell and developmental biology/epigenetics, cancer biology, bioengineering, and high-throughput screening, who will analyze (and store, if applicable) your samples. Your samples/data will be labeled with a unique study number. The outside laboratories will not know who you are. Private information such as your name, birth date or medical record number will not be shared with them.

- If you agree, your data will be shared through databases that may be publicly available to anyone. The data will not include identifiers like your name, medical record number or date of birth. To use your data, researchers must promise not to try to re-identify you. You can tell us at the end of this form whether you will allow is to share your data in this way.

By law, CHOP is required to protect your health information. The research staff will only allow access to your health information to the groups listed above. By signing this document, you are authorizing CHOP to use and/or release your health information for this research. Some of the organizations listed above may not be required to protect your information under Federal privacy laws. If permitted by law, they may be allowed to share it with others without your permission.

There is no set time for destroying the information that will be collected for this study. Your permission to use and share the information and data from this study will continue until the research study ends and will not expire. Researchers continue to analyze data for many years and it is not possible to know when they will be completely done.

Certificate of Confidentiality

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of Federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).
You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, medical care provider, or other person obtains your written consent to receive research information, then the researchers will not use the Certificate to withhold that information.

The Certificate of Confidentiality does not prevent the researchers from disclosing, without your consent, information that they are required by law to disclose to government authorities. For example, researchers must comply with laws requiring the reporting of suspected child abuse and neglect and communicable diseases.

Can you change your mind about the use of personal information?

You may change your mind and withdraw your permission to use and disclose your health information at any time. To take back your permission, you must tell the investigator in writing.

Dr. Jennifer M. Kalish, MD, PhD
The Children's Hospital of Philadelphia
Division of Genetics
3028 Colket Translational Research Building
3501 Civic Center Blvd
Philadelphia, PA 19104-4318

In the letter, state that you changed your mind and do not want any more of your health information collected. The personal information that has been collected already will continue to be used for the research. No new information will be collected. If you withdraw your permission to use your personal health information, you will be withdrawn from the study and the key that links your code to your information will be destroyed.

What are the financial considerations?

While you are in this study, the cost of your usual medical care – procedures, medications and doctor visits – will continue to be billed to you or your insurance.

Will there be any additional costs?

There will be no additional costs associated with participation in this study.

Will you be paid for taking part in this study?

You will not receive any payments for taking part in this study.

We may share your specimens and data with third parties (other researchers/institutions or for profit companies). If there are patents or products that result from the research, the third parties may make money from the research. You will not receive any financial benefit from research done on your specimens or data.

Who is funding this research study?

This study is funded by Children's Hospital of Philadelphia, Alex's Lemonade Stand Foundation, Damon Runyan Cancer Research Foundation, Rally Foundation, and St. Baldrick's Foundation.

What if you have questions about the study?

If you have questions about the study, call the study doctor, Dr. Jennifer Kalish, at 203-676-5283. You may also talk to your own doctor if you have questions or concerns.

The Institutional Review Board (IRB) at The Children's Hospital of Philadelphia has reviewed and approved this study. The IRB looks at research studies like these and makes sure research subjects' rights and welfare are protected. If you have questions about your rights or if you have a complaint, you can call the IRB Office at 215-590-2830.

Sharing Data with the National Institutes of Health (NIH)

Why will my data be shared with the National Institutes of Health (NIH)?

The NIH's goal is to maximize the benefits that come from the research.

The NIH repository stores genetic information and phenotypic data from many studies. The NIH then shares that information with researchers. We will send the information about you and the other participants to a repository at the NIH. The information will be de-identified (no names or other direct information about you will be included). The NIH will not be able to re-identify you or any other individual.

The NIH intends to share the collected information with other researchers. The researchers who receive data must promise to keep the data confidential and to use it only for the purpose approved by NIH. They must also promise to not try to re-identify anyone.
The goal of genetic studies is to look for genetic connections that may explain how to identify, prevent, and treat health problems. For example, genetic data may be used to find out:

- Who is more likely to develop a certain illness, such as asthma, cancer, or diabetes, or a condition like high blood pressure or obesity;
- What genes affect the progress of a certain disease or condition; and
- What genes may affect treatments which now may or may not work in certain people.

Risks Associated with Sharing Data with the NIH

There are risks associated with sharing your data with the NIH but they are very unlikely to occur. There is only a very small chance that someone could find out that the data came from you. If that happened, it's possible that someone could deny you a job or health insurance. Or you could experience stress, anxiety or embarrassment.

Benefits Associated with Sharing Data with the NIH

Sharing your information for future research will not directly benefit you. It is hoped that it will lead to a greater understanding of the interaction between genes and health. This knowledge could help others in the future.

Controlled or Unrestricted Access

The data about you can either be made available by the NIH through controlled access or unrestricted. Controlled access means the data are made available for other research only after investigators have obtained approval from NIH to use the requested data for a particular project. Data for unrestricted access are publicly available to anyone (e.g., The 1000 Genomes Project).

Consent to Share Data with the NIH

Please indicate whether you will allow us to share your information with the NIH by putting your initials next to one of the following choices:

_____ (initials) No, I do not consent to sharing my de-identified information with the NIH

_____ (initials) Yes, I do consent to sharing my de-identified information with the NIH for controlled access

_____ (initials) Yes, I do consent to sharing my de-identified information with the NIH for unrestricted access

OPTIONAL CONSENTS FOR THIS RESEARCH STUDY

Photographs and Audiovisual Recording (Optional)

As part of this research study, we would like to take photographs, or make films or audiovisual recordings of you (which may include images of your face which can identify you). If such images or recordings have already been taken/made as part of clinical care or another research study, we would like to use them for this study.

Please indicate whether you will allow us to take photographs and recordings (or use those taken of you in the past) by putting your initials next to one of the following choices:

For research analysis.	☐ Yes ☐ No Initials _____
For presentations to professional and/or medical groups.	☐ Yes ☐ No Initials _____
For publication in medical journals.	☐ Yes ☐ No Initials _____
For recruitment for this study including • Broadcasting (television, radio, internet, website) • Print media (newspapers, magazines) • Printed materials to advertise the registry (brochures, posters, etc.)	☐ Yes ☐ No Initials _____

Consent for Blood Sample (Optional)

We would like to draw a blood sample as part of this research study (as described above). Please indicate whether you will allow us to draw a blood sample by putting your initials next to one of the following choices:

I agree to you drawing a blood sample for this study.	☐ Yes ☐ No Initials _____

Consent for Skin Biopsy (Optional)

We would like to take a piece of your skin as part of this research study (as described above). Please indicate whether you will allow us to take a skin biopsy by putting your initials next to one of the following choices:

The procedure, risks and care of a skin biopsy were explained to me. **I agree to have a skin biopsy performed as part of this study.**	☐ Yes ☐ No Initials _____

Consent for every 6 month follow-up process (Optional)

Please also indicate whether we may update your clinical records and contact you because we need additional information every 6 months for this study by putting your initials next to one of the following choices:

I agree to be contacted every 6 months to provide additional information.	☐ Yes ☐ No Initials _____
I agree for my clinical information to be updated every 6 months.	☐ Yes ☐ No Initials _____

Consent for future research (Optional)

Please also indicate whether we may contact you for future research studies by checking a box and putting your initials next to one of the following choices:

I agree to be contacted for future research studies.	☐ Yes ☐ No Initials _____

Consent to Take Part in this Research Study and Authorization to Use and Disclose Health Information for the Research

The research study and consent form have been explained to you by:

Person Obtaining Consent	Signature of Person Obtaining Consent Date:

By signing this form, you are indicating that you have had your questions answered, you agree to take part in this research study, and if you are the parent of a child participant, you are legally authorized to consent to your child's participation. You are also agreeing to let CHOP use and share the health information collected as part of this research as explained above. If you do not agree to the collection, use and sharing of the health information, you (or the child participant) cannot participate in this study. **NOTE:** *A foster parent is not legally authorized to consent for a foster child's participation.*

Name of Subject	
Signature of Subject (18 years or older)	Date
Name of Authorized Representative (if different than subject)	Relation to subject: ☐ Parent ☐ Legal Guardian
Signature of Authorized Representative	Date

Child Assent to Take Part in this Research Study

For children capable of providing assent:

I have explained this study and the procedures involved to _____ in terms he/she could understand and that he/she freely assented to take part in this study.

_____
Person Obtaining Assent

_____ _____
Signature of Person Obtaining Assent Date

This study has been explained to me and I agree to take part.

_____ _____
Signature of Subject (optional) Date

For children unable to assent:

I certify that _____ was not capable of understanding the procedures involved in the study sufficiently to assent to study participation.

_____
Person Responsible for Obtaining Assent

_____ _____
Signature of Person Responsible Date

Questionnaire: Permission to Disclose Potentially Relevant Findings

The testing for this study will be conducted in a research laboratory. For a variety of reasons, research laboratory results are not considered valid for making clinical decisions.

It is possible that a research test might suggest a finding that could be of clinical importance. We will not contact you about every possible finding. Some things will not be disclosed including:

- Discrepancies in paternity.
- Findings whose significance is unknown.
- Findings for conditions which might increase risk for diseases seen late in life and for which there is no treatment.
- Results relating to a low or medium risk of a common disease of adulthood.
- Results relating to drug responsiveness.

If the research testing suggests findings that might be of importance for your medical care, you can be referred to a health professional who can repeat the test in a clinical laboratory. You will only be told about findings that if confirmed are:

- Findings (both disease-associated and suspected disease-associated changes) related to the condition for which you enrolled in this study.
- Findings that result in a high risk of developing a disorder with an important impact on health that requires immediate changes in medical care or treatment.
- Findings related to carrier status for a disease.
- Findings that result in a risk of developing a disorder in childhood with potential changes in your health care management.
- Findings that result in a risk of developing a disorder in adulthood with potential changes in your health care management.
- Findings that if confirmed could alter family planning.

Do you wish to be contacted to discuss any suggestive findings in general terms? You can decide at that time if you would like to be referred for further clinical care and repeat testing.

I would like to be told about suggestive findings that might be of importance to my clinical care.	☐ Yes ☐ No Initials _____
I would like to be told about suggestive findings that if confirmed could alter family planning.	☐ Yes ☐ No Initials _____

_____
Name of Subject

_____ _____
Signature of Subject (18 years or older) Date

_____ _____
Name of Authorized Representative (if different than subject) Relation to subject: ☐ Parent ☐ Legal Guardian

_____ _____
Signature of Authorized Representative Date

Child Assent: Permission to Disclose Potentially Relevant Findings

For children capable of providing assent:

I have explained this study and the procedures involved to _____ in terms he/she could understand and that he/she freely assented to take part in this study.

_____
Person Obtaining Assent

_____ _____
Signature of Person Obtaining Assent Date

This study has been explained to me and I agree to take part.

_____ _____
Signature of Subject (required) Date

For children unable to assent:

I certify that _____ was not capable of understanding the procedures involved in the study sufficiently to assent to study participation.

_____
Person Responsible for Obtaining Assent

_____ _____
Signature of Person Responsible Date

The Children's Hospital of Philadelphia
34th Street and Civic Center Boulevard, Philadelphia, PA 19104-4399

Clinical Genetics Center

Phone 215-590-2920 Fax 267-425-0007

REQUEST FOR MEDICAL INFORMATION/SAMPLES

Please return this form with your records.

Name of Institution, Practice, or Agency _____

Physician or medical staff _____

Address _____

Phone _____ Fax _____

This patient has been enrolled in a study being conducted by Dr. Jennifer Kalish and her colleagues. We would like to obtain as much clinical information as possible to understand their medical conditions. We would also like to collect samples left over from procedures (for example following surgical procedures or blood draws).
Please forward medical records, laboratory and imaging studies (in digital format if possible) to:
Mail: Attn: Jennifer Kalish, MD PhD
Division of Human Genetics
3028 Colket Translational Research Building
3501 Civic Center Blvd
Philadelphia, PA 19104
Fax: (267) 425-0007
Or Scan and email to: kalishj@chop.edu
If there are any questions, please feel free to contact me at the email address above or at (203) 676-5283.

Patient's Name _____ Date of Birth: _____

Mother's Name _____ Father's Name _____

Address _____

Information to be Released: ☐ Inpatient ☐Outpatient ☐ Genetics Records / Testing Results ☐ Other:_____

Expiration. Your permission will expire 1 year after you sign this form unless you indicate otherwise. _____.

I hereby authorize The Children's Hospital of Philadelphia to obtain my child's medical records with respect to any illness, injury, medical history, consultation, or treatment. I authorize the release of surgical or other samples.

This allows the release or obtaining of information that exists in the patient's medical record when the form is signed, as well as information created after the form is signed until it expires.

I may withdraw my permission at any time by providing written notice to the above-named provider releasing the information. For information being released by The Children's Hospital of Philadelphia, see its *Notice of Privacy Practices* for instructions on how to withdraw (revoke) an authorization. If I withdraw my permission, any information that was already released cannot be retrieved.

_____ _____ _____
Signature Print Name Date

Relationship to patient: ☐ Patient ☐ Parent ☐ Legal Guardian ☐ Other:_____

_____

Jennifer M. Kalish, MD, PhD
Attending Physician

Clinical and Molecular Studies of Growth and Epigenetic Alterations
IRB# 13-010658

Demographic Form (Optional)

Please complete the following information for you or your child. Please note that this form is optional and you can choose not to answer questions.

Gender

- ☐ Male
- ☐ Female

Race (please select all that apply)

- ☐ Caucasian/White
- ☐ African-American/Black
- ☐ Asian
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ Two or more races
- ☐ Other: _____

Ethnicity

- ☐ Hispanic/Latino
- ☐ Not Hispanic/Latino

Ancestry

Which countries are the mother and father's sides of the family from?

Examples: Italy, Germany, Puerto Rico, China, etc.

☐ My child is (or I am) adopted and the ancestry is unknown

Mother's Ancestry

_____

_____

_____

Father's Ancestry

_____

_____

_____

For completion by research staff: _____
(study number)

Registry Contact Form

If you agree to be contacted for a 6-month follow-up, future studies or potentially relevant findings, please let us know how you would like to be contacted:

Name of person to be contacted:

Relationship to Patient:

Address:

Phone:

Type: ☐ Cell ☐ Home ☐ Work

Type: ☐ Cell ☐ Home ☐ Work

Email:

Type: ☐ Personal ☐ Work

Type: ☐ Personal ☐ Work

Preferred Method of Contact

☐ E-mail ☐ Phone ☐ Mail

Preferred Language (if other than English):

Allowed Communication

☐ E-mail ☐ Phone ☐ Mail

Institutions List

Please list any hospitals, institutions, or names of physicians responsible for patient care:

Inpatient Records

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____

Outpatient Records

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____

Genetics Records

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____

OB / Birth Records

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____

Other Records

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____

If applicable, please list where the following are completed:

Ultrasound

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____

AFP blood draw

Name of Institution, Practice, or Agency_____
Physician or medical staff _____
Address _____
Phone _____
Fax _____