INFORMATION ABOUT THIS FORM

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

Please take time to review this information carefully. After you have finished, you should talk to the researchers about the study and ask them any questions you have. You may also wish to talk to others (for example, your friends, family, or other doctors) about your participation in this study. If you decide to take part in the study, you will be asked to sign this form. Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to you.

1. GENERAL INFORMATION ABOUT THIS STUDY AND THE RESEARCHERS

1.1 Study title: Molecular and Family Genetics of Autism and Autism Spectrum Disorders /Simons Simplex Collection

1.2 Company or agency sponsoring the study: The Simons Foundation

1.3 Names, degrees, and affiliations of the researchers conducting the study:
Catherine Lord, Ph.D
Director, the University of Michigan Autism and Communication Disorders Center (UMACC)
Professor of Psychology and Psychiatry
Research Scientist, Center for Human Growth and Development

2. PURPOSE OF THIS STUDY

2.1 Study purpose:
The University of Michigan Autism and Communication Disorders Center (UMACC) conducts clinical research seeking to advance understanding of autism spectrum disorders (ASD). For this study, we are collecting developmental and behavior information about you and your children. We are also collecting blood samples (DNA) from all participating family members. Developmental and behavioral information will be stored in a central databank. DNA will be stored in a central repository. Qualified researchers will access the databank and repository to look at how characteristics of ASD may be linked to specific genetic factors. In the event that researchers need additional information to further analyze findings, we will re-contact you and your family.

3. INFORMATION ABOUT STUDY PARTICIPANTS (SUBJECTS)

Taking part in this study is completely voluntary. You do not have to participate if you don't want to.

3.1 Who can take part in this study?

- Families who have one child with ASD can take part in this study. Families who have identical twins with ASD can also participate.

- Your child(ren) with ASD must:
  - Be 36 months of age or older
  - Have a minimum nonverbal IQ or nonverbal mental age of:
    - If between 36 months (4 years) old and 83 months: Nonverbal Mental Age of 24 months
    - If 84 months (7 years) and older: Nonverbal Mental Age of 30 months
  - Should not have a known genetic disorder, and
  - Should not have had extensive birth complications (prematurity, cerebral palsy, etc)

- Two biological parents must be willing to participate. Biological parents should not have ASD.
3.2 How many people (subjects) are expected to take part in this study?

This research study is being conducted at several different universities throughout North America. The number of families recruited at all of the sites combined will total at least 2000. At UMACC, we plan to recruit about 520 families into this study over the next three years.

4. INFORMATION ABOUT STUDY PARTICIPATION

4.1 What will happen to me in this study?

- **Parents** will complete standardized questionnaires, interviews and forms about their children’s behavior, development, medical history, and daily interactions. One of the interviews (the Autism Diagnostic Interview-Revised; ADI-R) will be videotaped so that the clinician and another person can verify the assessment of the participant with ASD. Parents will also complete standardized questionnaires about each other’s behavior; feedback about these questionnaires will not be provided.

There is a possibility that we may want to use the videotape of your family’s ADI-R for training and reliability purposes. If you agree to this, the ADI-R videotape may be viewed by clinicians who conduct this research study at different universities. At no time would these clinicians receive any information that would directly identify you or your family (e.g.; last names, addresses, dates of birth, etc.) Your decision regarding outside use of your family’s ADI-R videotape will not affect your family’s participation in this research study.

Please sign and check the appropriate box below to indicate your preference.

- I allow the videotape of the ADI-R to be used for training and reliability purposes.
- I do NOT allow the videotape of the ADI-R to be used for training and reliability purposes.

Signed: ___________________________ Date: ________________

- **Participants with ASD** will complete a battery of standardized tests to measure verbal, nonverbal, and social-communication skills. One of the tests (the Autism Diagnostic Observation Schedule; ADOS) will be videotaped so that the clinician and another person can verify the assessment of the participant with ASD. Parents will receive a brief written report summarizing the results of this session. Some participants with ASD may have previously completed some or all of these tests. These tests may need to be redone for this study, if:

  - The tests were last completed when the participant with ASD was less than four years old, OR
  - The tests were completed more than three years ago.

There is a possibility that we may want to use the videotape of your child’s ADOS for training and reliability purposes. If you consent to this, the ADOS videotape may be viewed by clinicians who conduct this research study at different universities. At no time would these clinicians receive any information that would directly identify you or your family (e.g.; last names, addresses, dates of birth, etc.) Your decision regarding outside use of the ADOS videotape will not affect your family’s participation in this research study.

Please sign and check the appropriate box below to indicate your preference.

- I allow the videotape of the ADOS to be used for training and reliability purposes.
- I do NOT allow the videotape of the ADOS to be used for training and reliability purposes.

Signed: ___________________________ Date: ________________

All participants with ASD will have a physical exam. Researchers will use information from the exam to look at how body features may be related to the genetics of autism.
All participants will have height, weight and head circumference measured. Head and face 3D digital scans will be completed and a standard set of pictures will be taken to allow researchers to look at how facial/head features may be related to the genetics of autism.

All participants will have blood drawn. In rare instances, if blood or biospecimen are insufficient for the participant to complete the protocol or the participant is unable to complete the protocol in one visit, it may be necessary to re-contact the participant's family and bring them in for additional blood draws and protocol completion. About three tablespoons or 40 cc of blood will be collected for research genetic analysis. Two genetic tests, Fragile X testing and array based cytogenetics, will be completed for all participants with ASD as a screening procedure.

After blood has been collected from participating family members, it will be sent to Rutgers University Cell and DNA Repository (RUCDR). RUCDR collects, maintains and distributes all specimens associated with this study. DNA will be extracted from specimens and stored indefinitely at RUCDR. A small amount of each family member's blood will be stored with the University of Michigan Pediatric Genetics department. The University of Michigan Pediatric Genetics Department may isolate DNA from this sample and use it for candidate gene sequencing.

De-identified information will be stored in a central databank associated with this study. This de-identified information may include demographic, medical, developmental, and behavioral information collected at UMACC. Data obtained from the 3D digital scan performed on you and your participating family members will be sent to Harvard University and the University of Missouri - Columbia for analysis. These data may be sent to and stored in the central databank. Qualified researchers will access the DNA at RUCDR and the de-identified information in the central databank to look at how characteristics of ASD may be linked to specific genetic factors.

The standard set of pictures taken of your family will be sent to the University of Missouri - Columbia for analyses.

One of the forms completed as part of this research study is associated with the National Database for Autism Research (NDAR). NDAR is a program created by the National Institutes of Health (NIH). The information collected from this form allows NDAR to create a unique subject number that will allow researchers to see if your family has been involved in more than one autism research study. If your family has participated in more than one autism research study, this unique subject number may prevent any incorrect duplication of findings. This subject number will also allow your de-identified data to be combined via NDAR with data from other research studies to increase the likelihood of meaningful analysis findings. Only this subject number and not your personal identifiable information will be accessible to NDAR.

All procedures completed as part of this research study are paid for through the study sponsor (The Simons Foundation). At no time will you or your insurance be billed for these research procedures. Some of the research procedures are similar to those provided by the UMACC clinic. If your family wants to pursue additional services through the UMACC clinic, we will refer you to our clinic office. Any additional clinic services are not part of this research study and would be billed to your family or your family's insurance.

It is likely that researchers will need additional information to further analyze genetic findings. If this occurs, we will re-contact you for follow-up information. If you are not comfortable with this, you should not provide consent. In the box below, please provide alternate contact information in case we cannot contact you using your current contact information.

Alternate Contact Information for Possible Follow-Up:
Study ID: HUM00002515 IRB: IRBMED Date Approved: 3/8/2011 Expiration Date: 10/10/2011

Name: ___________________________ Relationship: __________________________
Address: ___________________________
Phone Number: ___________________________ Alternate Phone Number: ___________________________
E-mail (optional): ___________________________

All information obtained as part of this study will be put into the UMACC Data Bank. The information will be available for researchers to use in research about autism and other social-communication disorders to answer questions about etiology, diagnosis, development, and response to treatment. Your name and other identifying information will be removed. If you do not feel comfortable with this, you should not provide consent.

4.2 How much of my time will be needed to take part in this study?
The evaluation part of the study requires about 4.5 to 7 hours of your time, and 2.5 to 4 hours of your child with ASD’s time. The blood draw [or saliva collection] requires about 20 minutes for each family member to complete. All study procedures will generally be scheduled over the course of 1 to 3 months. It is likely that researchers will need additional information to further analyze genetic findings. If this occurs, we will re-contact you for follow-up information.

4.3 When will my participation in the study be over?
In addition to the time above, qualified researchers who have permission to access the central databank and repository will access your information (i.e., de-identified data, DNA), to analyze the genetics of ASD. The central databank and repository will be available for researchers indefinitely. If researchers need additional information to further analyze any findings, we will contact you for follow-up information. If you are not comfortable with this, you should not provide consent.

Additional Research Studies: As described in this document, there may be additional information needed to further analyze findings for this study, and you will be contacted for this follow-up information. However you may be interested in additional studies on ASD or related disorders beyond the scope of the study described in this document. External researchers analyzing the databank or repository may develop new research questions that result in new research studies for which you may be eligible. Your decision on being contacted in the future about these opportunities will not affect your family’s participation in this current research study.

Please sign and check the appropriate box below to indicate your preference

☐ I am willing to be contacted in the future about additional studies on ASD or related disorders for which members of my family may be eligible. My consent to be contacted in no way obligates me or my family members to participate in such future studies, just to learn more about them and to decide at that time whether we wish to participate. UMACC can contact me to tell me about these new studies. If after hearing more about the study I am interested in participating, UMACC may share my contact info (name, address, phone number and date of birth) and SSC ID with other researchers, and will inform me when they do that.

☐ I am willing to be contacted in the future about additional studies on ASD or related disorders for which members of my family may be eligible. My consent to be contacted in no way obligates me or my family members to participate in such future studies, just to learn more about them and to decide at that time whether we wish to participate.
5. INFORMATION ABOUT RISKS AND BENEFITS

5.1 What risks will I face by taking part in the study? What will the researchers do to protect me against these risks?

Since the evaluation portion of this study takes between 2.5 and 4 hours of your child with ASD’s time, there is a risk that he/she may become bored or tired. This amount of time is typical for an evaluation so we minimize this risk by allowing breaks and snacks as needed. We will take breaks and can reschedule as necessary.

You may experience mild discomfort when blood is collected. After the blood draw, you may feel soreness or tingling in your arm. Some participants may experience bleeding, a small bruise, clot, or infection at the site of the blood draw. In rare situations, the blood draw may cause you to feel tired (fatigue), and lightheadedness and/or fainting may occur. A minority of participants may feel nauseous and/or vomit during or after the blood draw. Care will be taken to avoid all complications.

Genetic analyses of your DNA may find that you or a family member has a genetic or a chromosomal disorder. If we find meaningful genetic information we will inform you of this information, unless you request that we do not do so. We may refer your family for further clinical evaluation and refer you for genetic counseling unless you request that we do not do so.

Regarding action in the event that information of medical significance is found during the course of this study:

At this early stage of genetic research in autism, we do not anticipate finding meaningful genetic information of use to you. However, if we do find any information of use to you, we will inform you of this information and may refer your family for further clinical evaluation. You are given the option of not being contacted in the event that we find meaningful genetic information.

Please sign and check the appropriate box below to indicate your preference.

☐ I would like to be contacted to discuss medically significant findings.

☐ I would NOT like to be contacted to discuss medically significant findings.

Signed: ___________________________ Date: ___________________________
During the genetic analysis of your DNA, there is a possibility that researchers may reveal that you are not biologically related to your other family members who participated in this study. If this occurs, at no time will this information be disclosed.

We will take standard precautionary measures to protect confidentiality. However, it is possible that a breach of confidentiality (i.e., a loss of privacy) could occur and insurance companies or current or potential employers would acquire the genetic information obtained from this study. Currently, laws are being considered to address the confidentiality of genetic information, but there is little or no legal protection at this time against discrimination on the basis of genetic information.

To help protect you and/or your child’s privacy, we, the investigators of this study, have obtained a Certificate of Confidentiality from the National Institutes of Health, part of the U.S. Department of Health and Human Services (DHHS), an agency of the U.S. Government.

With this Certificate, we, the investigators, cannot be forced (e.g., by court subpoena) to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. Be aware that disclosure of you and/or your child’s identity may be found necessary, however, upon request of DHHS for the purpose of audit or evaluation.

You should also understand that a Confidentiality Certificate does not prevent you or a member of your family from voluntarily releasing information about your child, yourself, or your involvement in this research. Note however, that if an insurer or employer learns about you and/or your child’s participation, and obtains your consent to receive research information, then the investigator may not use the Certificate of Confidentiality to withhold this information. This means that you and your family must also actively protect your own privacy.

We are also asking your consent to provide research data and related findings to the National Database for Autism Research (NDAR). As described in section 4.1, NDAR is a biomedical informatics system and data repository, created by the National Institutes of Health to assist biomedical researchers working to develop a better understanding of autism and/or to develop more effective methods to diagnose, treat and prevent autism spectrum disorders.

Data entered into NDAR will be kept confidential, with NDAR being designed for access by researchers only. Data provided to NDAR as part of you and/or your child’s participation in this research study will be de-identified—i.e., you and/or your child’s name will be separated from the data. However, since this institution and others submitting data to NDAR will retain individually identifying information related to the data they provide, NIH has issued a legislatively authorized “Certificate of Confidentiality” that will help NDAR and participating institutions avoid being forced to disclose information that may identify you as an NDAR participant in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings.

Finally, you should understand that we, the investigators, are not prevented from taking steps, including reporting to authorities, to prevent serious harm to you, your child, or others. With respect to you and/or your child’s participation in NDAR, we do not plan to make voluntary disclosures except if there were severe threats to the public health or safety.

As with any research study, though, there may be additional risks of participating that are unforeseeable or hard to predict.
5.2 What happens if I get hurt, become sick, or have other problems as a result of this research?
The researchers have taken steps to minimize the risks of this study. Even so, you may still have problems or side effects, even when the researchers are careful to avoid them. Please tell the researchers listed in Section 10 about any injuries, side effects, or other problems that you have during this study. You should also tell your regular doctors.

5.3 If I take part in this study, can I also participate in other studies?
Being in more than one research study at the same time, or even at different times, may increase the risks to you. It may also affect the results of the studies. You should not take part in more than one study without approval from the researchers involved in each study.

5.4 How could I benefit if I take part in this study? How could others benefit?
We cannot promise that you personally will receive any benefits from being in this study. This study may help us to better understand the genetics of ASD. However, this information may not directly benefit you. Individuals with ASD in the future, their family members and future generations may benefit if we can find genes related to ASD. We do not expect to discover any information of direct clinical relevance to you in the near future.

5.5 Will the researchers tell me if they learn of new information that could change my willingness to stay in this study?
Yes, the researchers will tell you if they learn of important new information that may change your willingness to stay in this study. If new information is provided to you after you have joined the study, it is possible that you may be asked to sign a new consent form that includes the new information. If any new information is discovered that may affect your eligibility to continue to participate in the study, the researchers will contact you.

6. OTHER OPTIONS

6.1 If I decide not to take part in this study, what other options do I have?
Participation in this study is voluntary. You may refuse to participate or leave the study at any time. This will not affect the care you are currently receiving or the care you may receive in the future at UMACCC or the University of Michigan Hospital System.

7. ENDING THE STUDY

7.1 If I want to stop participating in the study, what should I do?
You are free to leave the study at any time. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record. If you decide to leave the study before it is finished, please tell one of the persons listed in Section 10 “Contact Information” (below).

7.2 Could there be any harm to me if I decide to leave the study before it is finished?
There is no foreseeable harm if you should decide to leave this study before it is finished.

7.3 Could the researchers take me out of the study even if I want to continue to participate?
Yes. There are many reasons why the researchers may need to end your participation in the study. Some examples are:
✓ The researcher believes that it is not in your best interest to stay in the study.
✓ You or your family becomes ineligible to participate.
✓ The study is suspended or canceled.

8. FINANCIAL INFORMATION

8.1 Who will pay for the costs of the study? Will I or my health plan be billed for any costs of the study?
Study ID: HUM00002515 IRB: IRBMED Date Approved: 3/8/2011 Expiration Date: 10/10/2011

There are no costs or billing for this study. Your family will be compensated for any parking costs associated with this study. If you receive a bill for any procedures completed as part of this study, please call the researchers’ number listed in section 10.1.

If complications occur as a result of this study, the researchers or the University of Michigan will help arrange for medical treatment, including, if necessary, emergency treatment. This study does not, however, pay for these costs. They may be billed to your insurer. You may have to pay for these costs if you health insurance does not cover them.

By signing this form, you do not give up your right to seek payment if you are harmed as a result of being in this study.

8.2 Will I be paid or given anything for taking part in this study?
For completing and returning the initial questionnaire packet, a $25 Visa Gift Card will be sent to your family, as compensation for your time. For completing the remainder of the study, including the blood draw or saliva collection, each participating family member will receive a $50 Visa Gift Card as compensation for your time and travel expenses related to this study.

8.3 Who could profit or financially benefit from the study results?
Dr. Catherine Lord, along with the other authors of some of the instruments used in the testing session of children with ASD, receives 1% of the profit in royalties from the distribution of these instruments when they are used at other institutions. Profits from the use of the instruments at UMACC are donated to charity.

UMACC will receive monetary compensation for exceeding the minimum amount of families enrolled per quarter.

You will not be compensated for any commercially valuable products that may be developed or are discovered as a result of the research funded in this study.

9. CONFIDENTIALITY OF SUBJECT RECORDS AND AUTHORIZATION TO RELEASE YOUR PROTECTED HEALTH INFORMATION

The information below describes how your privacy and the confidentiality of your research records will be protected in this study.

9.1 How will the researchers protect my privacy?
All information collected about you and your family members will be maintained in a manner specified by professional ethics and codes. Written records, videotapes, and photographs will be kept in locked cabinets in locked offices at UMACC.

If you consent to allow your family’s videotaped ADI-R and/or ADOS to be used for training and reliability purposes, it they will only be watched by clinicians associated with this research study at different universities. No information will be provided to these clinicians that would directly identify your family (e.g.: last names, addresses, dates of birth, etc.).

All information will be maintained in a password-protected, electronic database on a firewall-protected server. We shall not allow anyone to see your record, other than people who have a right to see it. All research records will be kept indefinitely after the study ends.

All original 3D image data sent to Harvard University and the University of Missouri - Columbia for analysis will be labeled with a unique identification code and will not contain your name or any other personal information. Data and images will be kept secure, with computer information kept in a password-protected computer on a firewall-protected server. 3D images generated from the data cannot be seen without a password and proprietary software. 3D image print-outs will be kept in a locked file cabinet in a locked office. Only researchers at Harvard University and the University of Missouri - Columbia who are analyzing the 3D image data have access to the password and 3D image print-outs.
After analysis is complete, all analysis data may be transferred to the central databank. All 3D images and original image data will be retained at Harvard University and the University of Missouri - Columbia under the secure conditions described above.

Your family’s standard set of pictures will be sent to the University of Missouri – Columbia on a password protected CD. All pictures will be labeled with a unique identification code and will not contain your name or any other personal information. Any print outs of the pictures will be kept in a locked file cabinet in a locked office. Only researchers at the University of Missouri – Columbia who are analyzing these pictures will have access to the CD password and print-outs. The pictures will be retained at the University of Missouri – Columbia under the secure conditions described above.

The data from the form associated with NDAR will be entered into a local program that converts the data into strings, encrypts it and sends it to a server at NIH. The encrypted strings are stored in the NIH database and used to generate a unique identifier. No personal information will be shared with NIH. The encryption method is designed to be extremely secure, to prevent converting the string back to your original identifying information.

All information sent to the central databank, the Rutgers University Cell and DNA repository (RUCDR) and the University of Michigan Pediatric Genetics Department will be labeled with a unique identification code. This code does not contain your name or any other personal identifying information. All data stored in the central databank, RUCDR, and the University of Michigan Pediatric Genetics Department is de-identified. To link the data to your personal files, access to a coding sheet, or “key,” is required. This sheet will contain your name and the unique code. It will be maintained electronically in a secure database and a hard copy will be kept in a locked file cabinet in a locked office at UMACC. Only UMACC research staff members will have access to this coding sheet.

Your privacy will be protected by federal, state, and local law. When required by law, the records of this research may be reviewed by the Federal Food and Drug Administration (FDA).

9.2 What information about me could be seen by the researchers or by other people?

Why? Who might see it?

Signing this form gives the researchers your permission to obtain, use, and share information about you for this study, and is required in order for you to participate in the study. Information about you may include information about your health and your medical care before, during, and after the study, even if that information wasn’t collected as part of this research study. For example:

- Mental health care records (except psychotherapy notes not kept with your medical records)
- Medical history records
- All records relating to the treatment you have received at UMACC.

There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- The researchers may need the information to make sure you can take part in the study.
- Study sponsors or funders, or safety monitors or committees, may need the information to make sure the study is done safely and properly and analyze the results of the study.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, social security number, payment amount, and related information for tax reporting purposes.
- The results of this study could be published in an article, but would not include any information that would let others know who you are.
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
Federal or State law may require the study team to give information to government agencies. For example, to prevent harm to you or others, or for public health reasons.

9.3 What happens to information about me after the study is over or if I cancel my permission?

As a rule, the researchers will not continue to use or disclose information about you, but will keep it secure until it is destroyed. Sometimes, it may be necessary for information about you to continue to be used or disclosed, even after you have canceled your permission or the study is over. Examples of reasons for this include:

- To avoid losing study results that have already included your information
- To provide limited information for research, education, or other activities (This information would not include your name, social security number, or anything else that could let others know who you are.)
- To help University and government officials make sure that the study was conducted properly

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System’s privacy policies. For more information about these policies, ask for a copy of the University of Michigan Notice of Privacy Practices. This information is also available on the web at http://www.med.umich.edu/hipaapnp.htm. Note that once your information has been shared with others as described under Question 9.2, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

9.4 When does my permission expire?

Your permission will not expire unless you cancel it. You may cancel your permission at any time by writing to the researchers listed in Section 10 "Contact Information" (below).

10. CONTACT INFORMATION

10.1 Who can I contact about this study?

Please contact the researchers listed below to:

- Obtain more information about the study
- Ask a question about the study procedures or treatments
- Report an illness, injury, or other problem (you may also need to tell your regular doctors)
- Leave the study before it is finished
- Express a concern about the study

Principal Investigator: Dr. Catherine Lord
Mailing Address: 1111 East Catherine Street
Ann Arbor, Michigan 48109-2054
Telephone: (734) 936-8600

Study Manager: Dr. Barbara Hanna
Mailing Address: 1111 East Catherine Street
Ann Arbor, Michigan 48109-2054
Telephone: (734) 936-8600

You may also express a concern about a study by contacting the Institutional Review Board listed below, or by calling the University of Michigan Compliance Help Line at 1-888-296-2481.

University of Michigan Medical School Institutional Review Board (IRBMED)
2800 Plymouth Road, Building 200, room 2086
Ann Arbor, MI 48103-4943
Telephone: 734-763-4768
Fax: 734-615-1622
e-mail: irbmed@umich.edu
Study ID: HUM00002515  IRB: IRBMED Date Approved: 3/8/2011  Expiration Date: 10/10/2011

If you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-888-296-2481.

When you call or write about a concern, please provide as much information as possible, including the name of the researcher, the IRBMED number (at the top of this form), and details about the problem. This will help University officials to look into your concern. When reporting a concern, you do not have to give your name unless you want to.

### 11. RECORD OF INFORMATION PROVIDED

#### 11.1 What documents will be given to me?

Your signature in the next section means that you have received copies of all of the following documents:

- This "Consent to be Part of a Research Study" document. *(Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record).*

- Other (specify): UMACC Data Bank Fact Sheet

### 12. SIGNATURES

#### Research Subject

I understand the information printed on this form. I have discussed this study, its risks and potential benefits, and my other choices with __________________________. My questions so far have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed in Section 10 (above). I understand that I will receive a copy of this form at the time I sign it and later upon request.

Signature of Subject: ___________________________________________  Date: __________

Name (Print legal name): ___________________________________________  Date of Birth: __________

#### Consent to allow information to be collected about me:

I understand that ___________________________ will be asked to complete standardized questionnaires about my behavior. I understand that I will not have access to or be provided feedback about this information.

I have discussed this study, its risks and potential benefits, and my other choices with __________________________. My questions about this aspect of the study have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed in Section 10 (above). I understand that I will receive a copy of this form at the time I sign it and later upon request.

Name of Subject (Print legal name): ________________________________

DO NOT CHANGE THIS FIELD—IRB USE ONLY

Page 11 of 12  Consent Subtitle: Biological Parents  Consent Version: 5.0-000C
**Principal Investigator (or Designee):**

I have given this research subject (or his/her legally authorized representative, if applicable) information about this study that I believe is accurate and complete. The subject has indicated that he or she understands the nature of the study and the risks and benefits of participating.

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<tr>
<th>Name: ___________________________</th>
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**Study ID:** HUM0002515  **IRB: IRBMED**  **Date Approved:** 3/8/2011  **Expiration Date:** 10/10/2011

**Signature:** ___________________________  **Date:** ___________________________