University of North Carolina at Chapel Hill
Short Form for Informed Consent to Participate in a Research Study

Title of Study: Research Participant Registry for the Carolina Institute for Developmental Disabilities

IRB Study # 01-0843

Principal Investigator: Renée D. Clark, M.S.W.

UNC-Chapel Hill Phone Number: (919) 966-5232

The UNC Research Registry is a list of individuals with autism spectrum disorders who agree to be contacted about research studies on autism and related conditions.

The purpose of the Research Registry is to help researchers who study autism and autism treatments find participants for their studies. By agreeing to be in the Registry, you are NOT agreeing to be in a study, you are agreeing to let us send you information about studies in the future. The Registry will send you information (by mail or email) about a specific study if you may be eligible. You can then decide whether or not you want to participate.

You may not benefit directly by being in the Registry, but your participation will help us learn more about how to diagnose and treat autism. Sometimes research studies involve risk. You will be informed about the possible risks (and benefits) for any research study. The risk involved in being in the Registry is low, because we protect your personal information by using security procedures designed to safeguard your privacy and prevent disclosure of information.

Enrolling in the Research Registry is voluntary. If you agree to be in the Registry, this means we will keep information about you in order to contact you in the future about any research studies that may be of interest to you. This information includes your name, birthdate, race, contact information, parents and siblings’ names, and a brief summary of results from a diagnostic evaluation for an autism spectrum disorder. Someone from the Registry office will contact you once each year to see if your address and phone number are correct.

We will keep you in the Registry until you ask us to remove your information. You may change your mind at any time in the future and request to have your name removed. There is no penalty for withdrawing from the Research Registry.

You have the right to ask, and have answered, any questions you may have about this Research Registry. If you have questions or complaints, you should contact Renée Clark by phone toll-free 1-866-744-7879 or email rdclark@email.unc.edu.

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by e-mail to IRB_subjects@unc.edu.
Signature of Research Subject

Printed Name of Research Subject

Signature of Witness (oral interpreter may sign as witness)

Printed Name of Witness

Signature of Research Team Member Obtaining Consent

Printed Name of Research Team Member Obtaining Consent

Date
University of North Carolina at Chapel Hill
HIPAA Authorization for Use and Disclosure of Health Information for Research Purposes

IRB Study # 01-0843

Title of Study: Research Participant Registry for the Carolina Institute for Developmental Disabilities

Principal Investigator: Renée D. Clark
Mailing Address for UNC-Chapel Hill Department: CB:3366, Chapel Hill, NC 27599-3366

This is a permission called a “HIPAA authorization.” It is required by the “Health Insurance Portability and Accountability Act of 1996” (known as “HIPAA”) in order for us to get information from your medical records or health insurance records to use in this research study.

1. If you sign this HIPAA authorization form you are giving your permission for the following people or groups to give the researchers certain information (described in #2 below) about you:
   Any health care providers or health care professionals that have provided health services or diagnostic evaluations for you such as physicians, clinics, hospitals, diagnostics centers, laboratories, including but not limited to the UNC Health Care System.

2. If you sign this HIPAA authorization form, this is the health information about you that the people or groups listed in #1 may give to the researchers to use in this research study:

   Diagnostic testing for an Autism Spectrum Disorder or a Developmental Disability, including genetic testing, DSM diagnoses codes and the most recent available assessment results from the following domains: 1) cognitive testing; 2) adaptive behavior ratings, 3) autism evaluation measures such as the Childhood Autism Rating Scale, the ADOS, and the ADI-R, and 4) language and educational testing.

3. The people or groups listed in #1 on this form may give this health information to the researcher listed at the top of this form (UNC-Chapel Hill Principal Investigator) or to another researcher working on this research study. This information may also be shared with, used by or seen by the sponsor of the research study, the sponsor’s representatives, officials of the IRB, and certain employees of the university or government agencies if needed to oversee the research study.

4. The HIPAA rules that apply to your medical records will not apply to your information in the research study records. The informed consent document describes the procedures in this research study to protect your personal information. You can also ask the researchers any questions about what they will
do with your personal information and how they will protect your personal information in this research study.

5. If you want to participate in this research study, you must sign this HIPAA authorization form to allow the people or groups listed in #1 on this form to give access to the information about you that is listed in #2 on this form. If you do not want to sign this HIPAA authorization form, you cannot participate in this research study but not signing the authorization form will not change your right to treatment, payment, enrollment or eligibility for medical services outside of this research study.

6. This HIPAA authorization will not stop unless you stop it in writing.

7. You have the right to stop this HIPAA authorization at any time. HIPAA rules are that if you want to stop this HIPAA authorization, you must do that in writing. You may give your written stop of this HIPAA authorization directly to the people or groups listed in #1 on this form or you may give it to the researcher and tell the researcher to send it to any person or group the researcher has given a copy of this HIPAA authorization. Stopping this HIPAA authorization will not stop information sharing that has already happened.

8. You will be given a copy of this signed HIPAA authorization.

____________________________________  __________
Signature of Research Subject         Date

____________________________________
Print Name of Research Subject

For Personal Representative of the Research Participant (if applicable)

Print Name of Personal Representative: ___________________________
Please explain your authority to act on behalf of this Research Subject:

____________________________________________________________

I am giving this permission by signing this HIPAA Authorization on behalf of the Research Participant.

____________________________________  __________
Signature of Personal Representative         Date
ADULT RESEARCH REGISTRY INFORMATION FORM
(Please Print)

**PARTICIPANT INFORMATION**

<table>
<thead>
<tr>
<th>First Name</th>
<th>Middle</th>
<th>Last</th>
<th>Suffix</th>
<th>Nick Name</th>
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- Jr.  - III
- Sr.  - IV.

**Gender at birth**

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
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</table>

**Birth date:**

/ / /

**Vocational & Educational Status (check all that apply)**

- full or part time student
- Employed part-time
- Employed full-time
- Day program
- Other, specify:

**Contact Information**

**Mailing Address/ Street or PO Box Number:**

<table>
<thead>
<tr>
<th>City:</th>
<th>State:</th>
<th>ZIP Code:</th>
<th>NC County:</th>
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</table>

**Primary phone:**

( )

**Alternate phone:**

( )

**Email:**


**Race:**

- American Indian or Alaskan Native
- Asian
- Hawaiian/ Other Pacific Islander
- More than one race

**Ethnicity:**

- Hispanic or Latino
- NOT Hispanic or Latino

**Black/ African American**

- White/Caucasian
- Other, specify:

**Language**

**Is English your primary language?**

- YES  - NO

**All Languages spoken:**

- English  - Spanish
- Other, specify:

**Education completed:**

- No high school diploma or GED
- High school diploma or GED
- Some college, but no degree
- Associate or technical degree
- BA, BS or 4-year college degree
- Graduate degree

**You live with:**

- Self
- Spouse
- Both biological parents
- Bio mother
- Bio father
- Adoptive parents
- Mother and stepparent
- Father and stepparent
- Other relatives
- Non-family care (group home)
- Friend or roommate
- Other

**Diagnostic and Medical History**

**Which term best describes your autism diagnosis?**

- Asperger’s disorder or High Functioning Autism (HFA)
- Autism, Autistic disorder, or Autism Spectrum disorder
- Pervasive developmental disorder-NOS (PDD-NOS)

**What type of professional made this diagnosis?**

- Pediatrician
- Psychologist
- Neurologist
- Psychiatrist
- Other:

**Approximate date of this diagnosis?**

**History of seizures:**

- None
- Current (including controlled by medication)
- Past, not present
**Sensory Impairments:**
- [ ] None
- [ ] Visually impaired (VI)
- [ ] Blind
- [ ] Hearing impaired (HI)
- [ ] Deaf
- [ ] VI and HI

**Any known genetic syndromes or other conditions?**
- [ ] None
- [ ] Name of syndrome
- [ ] Name of chromosome disorder
- [ ] Name of neurological or medical condition

**Any psychiatric conditions? (anxiety, depression, etc)**

**Do you have relatives who have been diagnosed with an autism spectrum disorder? (check all that apply)**
- [ ] None
- [ ] Sibling
- [ ] Your child
- [ ] A parent
- [ ] First cousin
- [ ] An aunt or uncle
- [ ] Other, specify

**Have you ever received services at a TEACCH Center? (in Chapel Hill, Greenville, Asheville, Charlotte, Gastonia, Wilmington, Greensboro, Raleigh, or Fayetteville?)**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**Have you ever received services at the UNC Center for Development and Learning (CDL) or the Carolina Institute for Developmental Disabilities?**
- [ ] Yes
- [ ] No
- [ ] I don’t know

**When is it most convenient for you to receive phone calls?**
- [ ] Mornings
- [ ] Afternoons
- [ ] Evenings
- [ ] Specify:

**How many studies per year would you like to be notified about?**
- [ ] All studies for which I may be eligible.
- [ ] Five, max
- [ ] Three, max
- [ ] Other, specify number

**Any other relevant information about yourself which may impact research participation** (Travel preferences, Transportation, study type preferences, etc.)

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**SECOND CONTACT**

Would you like to designate a second person (spouse, partner, parent, adult sibling) for us to send study information to in addition to yourself?

**First Name:**

**Last Name:**

**Relationship to you:**

**Mailing address/ street or PO Box:**

**City:**

**State:**

**ZIP Code**

**Email:**

**Primary phone:**

(______)

**Alternate phone:**

(______)