



The North Carolina Center for the Care of  
**Huntington's Disease**

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## **Notice of Privacy Practices for Protected Health Information**

***This document describes how your personal medical information may be used and disclosed and how you can get access to this information. Please read it carefully.***

### **I. Introduction**

The North Carolina Center for the Care of Huntington's Disease is an organization that in the course of its interaction with Huntington's Disease patients and families will come into contact with private medical and personal information. Because the inadvertent disclosure of this information could be detrimental to a patient or family member, the North Carolina Center for the Care of Huntington's Disease will follow guidelines established under the Patient Notification of Privacy Rights Health Insurance Portability and Accountability Act (HIPAA). Because NC-CCHD does not bill for services, we will not disclose any information to insurance companies, but include this information to better educate you about your rights and responsibilities as you interact with agencies or care providers to which we may refer you in the course of your treatment.

HIPAA provide protection for information shared between a health care provider and patient. Records are kept documenting your care as required by law, professional standards, and other review procedures. HIPAA defines what kind of information is to be included in your "designated medical record", including documentation of symptoms, examinations, test results, diagnoses, treatment, and future care or treatment. Additional information, known as "psychotherapy notes", document and analyze the contents of a conversation during a private, group or joint family therapy session, are more private and contain much more personal information about you. Psychotherapy notes are usually not accessible to insurance companies and third party reviewers, and in some cases, not to the patient himself/herself.

HIPAA provides privacy protections about your personal health information, which is designated as "protected health information" (PHI). PHI consists of three (3) components: treatment, payment and health care operations. Treatment refers to activities in which health care is provided, coordinated, or managed. Examples include a psychotherapy session, medication management session, communication with a primary care physician about medication or a medical condition, or coordinating care with another physician. Payment refers to activities related to obtaining reimbursement for medical care. An example of this would be the documentation provided, including diagnostic codes and treatment codes, for the purpose of filing claims with an insurance carrier. Health care operations are activities related to the performance of a medical practice. These include quality assessment, quality improvements, outcome evaluation, protocol and clinical guidelines development, continuing medical education activities, credentialing, medical review, legal services, insurance, etc. An example of health care operations is when utilization review occurs, a process in which an insurance company reviews services provided to see if your care is "medically necessary." "Disclosure" refers to the release of your private medical information to individuals or organizations outside the providing physician's office. An example of disclosure is sending protected health information to a primary care physician or an insurance company.

### **II. Uses and Disclosures of Protected Health Information (PHI) Requiring Authorization**

North Carolina law and HIPAA require authorization and consent for treatment, payment and healthcare operations. Your PHI may be disclosed for the purposes of treatment, payment and healthcare operations only with your consent. A general consent to care and authorization to conduct payment and health care operations authorizes a physician provide treatment and to conduct administrative steps associated with medical or mental health care.

When authorized, the minimum amount of information necessary will be disclosed. This may include the following: identifying paperwork completed when treatment began, billing information, initial assessment, mental status examinations, treatment plans, discharge summaries, progress notes, managed patient care reviews, diagnostic testing, and any authorization letters or summarizes of care requests to have completed on his or her behalf. Please note that the actual test questions or raw data of psychological tests, which are protected by copyright laws and the need to protect patients from unintended, potentially harmful use, are not part of the "designated mental health record."

Additionally, if you ever want any of your protected health information released unrelated to treatment, payment or health care operations, a specific authorization to release information to this outside party will need to be signed. A copy of that authorization form is available upon request. An example of this type of release of information might be a patient's request that their physician speak to an employer about the patient's medical needs. Before talking with an employer, that patient will need to have first signed the proper authorization or consent to release information.

There is a third, special authorization provision potentially relevant to the privacy of psychotherapy notes. In recognition of the importance of the confidentiality of conversations between a psychiatrist or therapist and patient in treatment settings, HIPAA

permits keeping “psychotherapy notes” separate from the overall “designated medical record.” Insurance companies cannot secure psychotherapy notes nor can they insist upon their release for payment of services as has unfortunately occurred over the last two decades of managed mental health care. Certain payers of care, such as Medicare and Workers Compensation, however, require the release of both your progress notes and psychotherapy notes in order to pay for your care. If an insurance company or other Third Party Payers requests psychotherapy notes in addition to progress notes for reimbursement of services rendered, you will be asked to sign an additional authorization to release them.

You may, in writing, revoke all authorizations to disclosure protected health information at any time. You cannot revoke an authorization for disclosures, which have been submitted, with your prior consent. Likewise, you cannot revoke authorization if the authorization was obtained as a condition for obtaining insurance, and North Carolina law provides the insurer the right to contest the claim under the policy.

### **III. Business Associates Disclosures**

HIPAA requires that clinicians work with, train and monitor the conduct of those performing ancillary administrative services supporting clinical practice and refers to these people as “business associates.” At NC-CCHD, “business associates” includes administrative and volunteer staff who provide services such as typing, making phone calls, and other administrative work. These activities bring them into some measure of contact with your protected health information. The staff does not have access to those sections of your designated record that contains the particulars of your health concerns; only physicians and clinical personnel directly involved in your care have access to your full-designated health record. Administrative and clinical records are separated in an attempt to further enhance your privacy. The only other “business associates” in the NC-CCHD office are subtenants or janitorial staff. In compliance with HIPAA, there is a formal contract with these business associates, that very clearly spells out the importance of protecting any health information as an absolute condition for employment or occupancy. These individuals are educated about privacy practices and compliance is monitored.

### **IV. Other Disclosures and Uses**

Communication with Family: Using our best judgment, we may disclose to a family member, relative, close personal friend, or any other person that you identify, health information relevant to that person’s involvement in your care if you do not object or in an emergency in which your safety or the safety of others is in doubt.

Notification: Unless you object, we may use or disclose your protected health information to notify a family member or other persons responsible for your care about your location, about your general condition, or about your death.

Food and Drug Administration: We may disclose to the FDA your protected health information relating to adverse events with respect to food, supplements, products and product defects, or post-marketing surveillance information to enable product recalls, repairs, or replacements.

Worker’s Compensation: If you are seeking compensation through Worker’s Compensation, we may disclose your protected health information to the extent necessary to comply with laws relating to Worker’s Compensation.

Abuse and Neglect: We may disclose your protected health information to public authorities as allowed by law to report abuse or neglect.

Public Health: As authorized by law, we may disclose your protected health information to public health or legal authorities charged with preventing or controlling disease, injury or disability; to report reactions to medications or problems with products; to notify a person who may have been exposed to a disease or who is at risk for contracting or spreading a disease or condition.

Grassroots and other HD Organizations: Several organizations have interest in the care and research of Huntington’s Disease, including the Huntington’s Disease Society of America, the Cure Huntington’s Disease Initiative, and the Huntington’s Study Group, to name a few. Your written consent will be required for release of any information to these organizations.

Employers: We may release health information about you to your employer if we provide health care services to you at the request of your employer, and the health care services are provided either to conduct an evaluation related to medical surveillance of the workplace or to evaluate whether you have a work-related illness or injury. In such circumstances, we will give you written notice of such release of information to your employer. Any other disclosure to your employer will be made only if you execute a specific authorization for the release of that information to your employer.

Correctional Institutions: If you are an inmate of a correctional institution, we may disclose to the institution or its agents the protected health information necessary for your health and the health and safety of other individuals.

Law Enforcement: We may disclose your protected health information for law enforcement purposes as required by law, such as when required by a court order, or in cases involving felony prosecution, or to the extent an individual is in custody of law enforcement.

Health Oversight: Federal law allows us to release your protected medical information to appropriate health oversight agencies or for health oversight activities.

Judicial/Administrative Proceedings: We may disclose your protected health information in the course of any judicial or administrative proceeding as allowed by law, or with your authorization, or as directed by a proper court order.

Serious threat: To avert a serious threat to health or safety, we may disclose your protected health information consistent with applicable law to prevent or lessen a serious, imminent threat to the health or safety of a person or the public.

For Specialized Governmental Functions: We may disclose your protected health information for specialize governmental

functions as authorized by law such as to Armed Services personnel, for national security purposes, or to public assistance program personnel.

Coroner or Medical Examiners: We may release health information to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or to determine the cause of death.

Other uses: Other uses and disclosures, besides those identified in this Notice, will be made only as required by law or with your written authorization. You may revoke the authorization as previously provided in this Notice under "Your Health Information Rights".

## **V. Patient's Rights**

The record that we maintain is the physical property of The North Carolina Center for the Care of Huntington's Disease. The information in it, however, belongs to you. You have a right to:

- Request restrictions on certain uses and disclosures of your protected health information by delivering the request in writing. We are not required to grant the request, but we will comply with any request granted.
- Obtain a paper copy of the current Notice of Privacy Practices for Protected Health Information ("Notice") by making a request at our office.
- Receive confidential communications by alternative means and at alternative locations. For example, you may not want mailed information sent to your home address. All information will be sent to another location of your choosing.
- Request that you be allowed to inspect and copy your protected health information.
- Appeal a denial of access to your protected health information, except in certain circumstances.
- Request that your health care record be amended to correct incomplete or incorrect information by delivering a request in writing to this office. We may deny the request if you ask to amend information that:
  - Was not created by us, unless the person or entity that created the information is no longer available to make the amendment.
  - Is not part of the health information kept by or for this office
  - Is not part of the information that you would be permitted to inspect or copy
  - Is accurate and correct
  - If your request is denied, you will be informed of the reason for the denial and will have an opportunity to submit a statement of disagreement to be maintained with your records.
- The right to an accounting of non-authorized disclosures of your protected health information.
- The right to revoke your authorization of your protected health information except to the extent that action has already been taken.

### **Organizational Duties**

NC-CCHD will:

- Maintain the privacy of your health information as required by law;
- Provide you with a notice as to our duties and privacy practices as to the information we collect and maintain about you;
- Abide by the terms of this notice;
- Notify you if we cannot accommodate a requested restriction or request; and,
- Accommodate your reasonable requests regarding methods to communicate health information with you.

We reserve the right to amend, change, or eliminate provisions in our privacy practices and access practices and to enact new provisions regarding the protected health information we maintain.

### **To Request Information or to File a Complaint:**

If you have questions, would like additional information, or want to report a problem regarding the handling of your medical information, you may contact *Mary C. Edmondson, MD, President of the North Carolina Center for the Care of Huntington's Disease at 1004 Dresser Court, Suite 107, Raleigh, NC 27609.*

If you feel that your privacy rights have been violated, you may file a written complaint at our office by delivering the complaint to Dr. Edmondson. You may also file a complaint to the Secretary of Health and Human Services (HHS). We cannot, and will not, require you to waive the right to file a complaint with the Secretary of Health and Human Services as a condition of receiving treatment from this organization. In addition, we will not retaliate against you for filing a complaint with the Secretary of HHS.

The Federal Medical Privacy Rule went into effect April 14, 2003 and will remain so until new notice provisions effective for all protected health information are enacted.