Notice of Privacy Practices

The Sickle Cell Disease Foundation of California (SCDFC) takes pride in treating our clients and each other with respect and dignity. Protecting your health information is very important to us. We want you to have a clear understanding of how we use and safeguard your protected health information, and how you can get access to that information.

A new federal law commonly known as HIPAA requires that we take additional steps to keep you informed about how we may use information that is gathered in order to provide health care services to you. As part of this process, we are required to provide you with the following Notice of Privacy Practices and to request that you sign the attached written acknowledgement that you received a copy of the Notice. The Notice describes how we may use and disclose your protected health information to carry out treatment, payment or health care operations and for other purposes that are permitted or required by law. This Notice also describes your rights regarding health information we maintain about you and a brief description of how you may exercise these rights.

If you have any questions about this Notice please contact the Sickle Cell Disease Foundation of California at 3602 Inland Empire Blvd., Suite B220, Ontario, CA 91764, (909) 743-5226.

SICKLE CELL DISEASE FOUNDATION OF CALIFORNIA
NOTICE OF PRIVACY PRACTICES

Effective April 14, 2003

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

Under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Sickle Cell Disease Foundation of California and all subsidiary operations (hereinafter referred to as the "Agency") must take steps to protect the privacy of your “protected health information” (PHI). PHI includes information that we have created or received regarding your health or payment for your health. It includes both your records and personal information such as your name, social security number, address, and phone number. We are also required to:

- Provide you with this Notice of Privacy Practices (which may be amended from time to time)
- Follow the practices and procedures set forth in the Notice.

For more information about our privacy practices, or for additional copies of this Notice, please contact the Sickle Cell Disease Foundation of California.

I. USES AND DISCLOSURES OF PROTECTED HEALTH INFORMATION

A. Permissible Uses and Disclosures without Your Written Authorization
We may use and disclose PHI without your written authorization for certain purposes as described below. The examples provided in each category are not meant to be exhaustive, but instead are meant to describe the types of uses and disclosures that are permissible under federal and state law.

1. Treatment: We may use and disclose PHI in order to provide treatment to you. For example, we may use PHI to diagnose and provide counseling service to you. In addition, we may disclose PHI to other health care providers involved in your treatment to the extent required or permitted by law.

2. Payment: We may use or disclose PHI so that services you receive are appropriately billed to, and payment is collected from, your health plan. By way of example, we may disclose PHI to permit your health plan to take certain actions before it approves or pays for treatment services. We will obtain your authorization for the release of PHI to your health insurance company, however, under the Agency's Fee Agreement and Service Provider Form.

3. Health Care Operations: We may use and disclose PHI in connection with our health care operations, including quality improvement activities, training programs, accreditation, certification, licensing or credentialing activities, and during supervision and/or consultation. Additionally, it is generally agency policy that when a client of the Agency is receiving service from more than one program, staff from one program may share information with staff of the other. Any information shared, however, will remain confidential and will only be that which is considered minimally necessary to ensure that appropriate service is provided our clients.

4. Your Authorization: In addition to our use of your health information for treatment, payment or healthcare operations, you may give us written authorization to use your health information or to disclose it to anyone for any purpose. If you give us an authorization, you may revoke it in writing at any time. Your revocation will not affect any use or disclosures permitted by your authorization while it is in effect. Unless you give us a written authorization, we cannot use or disclose your health information for any reason except for those described in this notice.

5. Required or Permitted by Law: We may use or disclose PHI when we are required or permitted to do so by law. For example, we may disclose PHI to appropriate authorities if we reasonably believe that you are a possible victim of abuse, neglect, or domestic violence or the possible victim of other crimes. In addition we may disclose PHI to the extent necessary to avert a serious threat to your health or safety or the health or safety of others.

Other disclosures permitted or required by law include the following:

- Disclosures for public health activities;
- Health oversight activities including disclosures to state or federal agencies authorized to access PHI;
- Disclosures in a legal proceeding in response to an order of a court or administrative agency and, in certain cases, in response to a subpoena, discovery request, or other lawful process;
- Disclosures for research when approved by an institutional review board;
- Disclosures to military or national security agencies, coroners, medical examiners, and correctional institutions or otherwise as authorized by law.
B. Miscellaneous Uses or Disclosures Without Your Authorization

1. **Appointment Reminders**: We may use or disclose your health information to provide you with appointment reminders (such as voicemail messages, postcards or letters).

2. **De-identify information** – To “de-identify” information by removing information from your PHI that could be used to identify you.

C. Uses and Disclosures Requiring Your Written Authorization

1. **Progress or Case Management Notes**: Notes recorded by a case worker documenting the contents of a counseling session with you or your family’s social history (“Progress or Case Management Notes”) generally will be used only by the case worker and will not otherwise be used or disclosed without your written authorization, with a few exceptions. Specific exceptions where an authorization is not required include use for certain operational purposes, such as supervision, and as permitted or required by law. Uses may also include defense of a legal action. We generally try to use or disclose such notes only to the minimum necessary. We may also review prior Progress or Mental Health Notes if you were seen previously at the Agency.

2. **Marketing Communications**: We will not use your health information for marketing communications without your written authorization.

3. **Records for Couples**: Records for couples who are seen together will not be released, under the examples noted in this section, without the prior written consent of both parties.

4. **Other Uses and Disclosures**: Uses and disclosures other than those described in Section I.A. above will only be made with your written authorization. For example, you will need to sign an authorization form before we can send PHI to your life insurance company, to a school, or to your attorney. You may revoke any such authorization at any time.

II. YOUR INDIVIDUAL RIGHTS

A. **Right to Inspect and Copy**. You may request access to your case record and billing record maintained by our agency in order to inspect and request copies of the records. All requests for access must be made in writing. Under limited circumstances, we may deny access to your records. We may charge a fee for the costs of copying and sending you any records requested. If you are a parent or legal guardian of a minor, please note that certain portions of the minor’s case record will not be accessible to you.

B. **Right to Alternative Communications**. You may request, and we will accommodate, any reasonable written request for you to receive PHI by alternative means of communication or at alternative locations.

C. **Right to Request Restrictions**. You have the right to request a restriction on PHI used for disclosure for treatment, payment or health care operations. You must request any such restriction in writing addressed to the Privacy Officer as indicated below. We are not required to agree to any such restriction you may request.

D. **Right to Accounting of Disclosures**. Upon written request, you may obtain an accounting of certain disclosures of PHI made by us after April 14, 2003. This right applies
to disclosures for purposes other than treatment, payment or health care operations, excludes disclosures made to you or disclosures otherwise authorized by you, and is subject to other restrictions and limitations.

**E. Right to Request Amendment:** You have the right to request that we amend your health information. Your request must be in writing, and it must explain why the information should be amended. We may deny your request under certain circumstances.

**F. Right to Obtain Notice.** You have the right to obtain a paper copy of this Notice by submitting a request to the Privacy Officer at any time.

**G. Questions and Complaints.** If you desire further information about your privacy rights, or are concerned that we have violated your privacy rights, you may contact the Sickle Cell Disease Foundation of California, 3602 Inland Empire Blvd., Suite B220, Ontario, CA 91764, (909) 743-5226.

You may also file written complaints with the Director, Office for Civil Rights of the U.S. Department of Health and Human Services. We will not retaliate against you if you file a complaint with the Director or the Agency.

**III. EFFECTIVE DATE AND CHANGES TO THIS NOTICE**

**A. Effective Date.** This Notice is effective on April 14, 2003.

**B. Changes to this Notice.** We may change the terms of this Notice at any time. If we change this Notice, we may make the new notice terms effective for all PHI that we maintain, including any information created or received prior to issuing the new notice. If we change this Notice, we will post the revised notice in the reception waiting area, or on our website at www.scdfc.org. You may also obtain any revised notice by contacting the Sickle Cell Disease Foundation of California.