Data Sharing Agreement

Between

_____ ("Clinic")

and

_____ ("Association")

This Data Sharing Agreement is entered into by and between:

_____ (hereinafter "Clinic"); and

_____ (hereinafter "Association")

for the purpose of sharing contact information for patients diagnosed with Sickle Cell Disease. When referred to collectively, Clinic and Association are referred to as the "Parties."

I. Background

In Act 647 of 2022, the Louisiana Legislature created the Sickle Cell Disease Registry, known as the "Skylar-Cooper Database", and tasked the Louisiana Department of Health ("LDH") with collecting patient information from healthcare providers around the state to connect patients with healthcare advocates and associations to assist individuals suffering with sickle cell disease.

In Act 748 of 2024, the Louisiana Legislature mandated LDH to "facilitate an agreement between sickle cell clinics as provided for in R.S. 40:1125.31 et seq, and an association that is part of the Louisiana Sickle Cell Commission that provides information and assistance to patients diagnosed with sickle cell disease. The agreement shall allow for the transfer of sufficient contact information from the sickle cell clinics to allow an association to contact the patient."

II. Purpose

LDH has prepared this Data Sharing Agreement for use by Louisiana Sickle Cell Clinics and Sickle Cell Associations to enable the transfer of contact information between them as mandated by Act 748 of 2024. The objective of this Agreement is to outline the roles and responsibilities of the Parties in implementing that transfer of data.

III. Procedure for Sharing of Patient Contact Information

A. As soon as practicable after the effective date of this Agreement, Clinic shall attempt to determine which of its current patients are already receiving services from a Louisiana Sickle Cell Association.

B. If Clinic finds that a patient is not already receiving services from a Louisiana Sickle Cell Association, or if it is unable to determine whether the patient is receiving such services, then:

1. Clinic shall determine which Louisiana Sickle Cell Association serves the area in which the patient resides.

2. Clinic shall contact any patient residing in the area served by Association, inform them of the services and benefits they can receive from Association, and inquire whether they would like to be put in contact with Association.

3. If the patient wishes to be put in contact with Association, they can choose one of the following options:
    a. Take responsibility for contacting Association directly, using contact information furnished to them by Clinic; or
    b. Request that Clinic forward the patient's contact information, as specified in Section IV below, to Association so that Association can contact the patient.

4. If the patient does not wish to be put in contact with Association, the refusal shall be noted in the patient's record and Clinic shall not pursue the inquiry any further.

5. If the patient chooses option III.B.3.a above, the choice shall be noted in the patient's record, Clinic shall give Association's contact information to the patient, and Clinic shall not pursue the inquiry any further.

6. If the patient chooses option III.B.3.b above, Clinic shall request that patient execute an authorization permitting Clinic to disclose the patient's contact information to Association. The authorization shall comply with the requirements of the HIPAA Privacy Rule, shall specifically name Clinic as the party disclosing the contact information, and shall specifically name Association as the party receiving the information.

7. If the patient chooses to execute the authorization, Clinic shall forward the patient's contact information, as specified in Section IV below, to Association, along with an original of the authorization. The patient's choice shall be noted in their record and the following shall be entered into the record:
    a. An exact copy of the contact information forwarded to the Association;
    b. An original or copy of the executed authorization; and
    c. The date, circumstances, and method of disclosure of the contact information to Association.

8. If the patient declines to execute the authorization, the refusal shall be noted in the patient's record and Clinic shall not pursue the inquiry any further.

C. Beginning on the effective date of this Agreement, Clinic shall also follow the procedure set forth in Sections III.A and III.B above with respect to new patients.

D. If the patient is a minor child or other individual who has a "personal representative" as defined in the HIPAA Privacy Rule (such as a parent, guardian, or power of attorney), the personal representative shall act on behalf of the patient in making the choices and executing the documents called for in Section III.B above.

E. The transfer of patient contact information pursuant to this Agreement shall be conducted by a method and with a frequency mutually agreeable to the Parties and shall comply with the requirements of the HIPAA Privacy Rule and of the HIPAA Security rule as applicable.

IV. Data Elements for Patient Contact Information

The patient contact information forwarded by Clinic to Association shall include only the following data elements, to the extent that they are known to Clinic:

- Patient Name (First, Middle, Last)
- Patient Date of Birth
- Name and Relationship of Personal Representative, if any
- Physical Address of Patient (or of Personal Representative if applicable)
- Mailing Address of Patient (or of Personal Representative if applicable)
- Phone Number(s) (home and/or mobile) of Patient (or of Personal Representative if applicable)
- Email Address of Patient (or of Personal Representative if applicable)

V. Term of Agreement; Modification

A. This Agreement shall become effective on the date of the last Party's signature and shall remain in effect until terminated in writing, either by one Party unilaterally or by agreement of both Parties.

B. This Agreement may be modified only by the written agreement of the Parties, duly signed by their authorized representatives. This Agreement may be reviewed routinely as needed.

[Signatures follow on next page]

VI. Signatures

For Clinic:	**For Association:**
_____	_____
Name of Clinic	Name of Association
_____	_____
Signature	Signature
_____	_____
Printed or Typed Name	Printed or Typed Name
_____	_____
Title	Title
_____	_____
Date	Date