St. Jude Children's Research Hospital | Department of Hematology
Sickle Cell Disease Personal Health Record

PERSONAL CONTACT INFORMATION

Last name:	First name:	MI:
Age:	Date of birth:	

Address:

City:	State:	Zip Code:

Home phone:	Cell phone

Email address:

Emergency contact	Phone:	Relationship:

What type of sickle cell disease do you have?

Do you receive SSI/Disability Benefits? ❑ Yes ❑ No

Do you have health insurance: ❑ Yes ❑ No

If yes, give the name of company and policy number (if known):

Do you have any other health issues (such as asthma or diabetes)? ❑ Yes ❑ No

If yes, what other health issues?

Are you allergic to any foods or medicines? ❑ Yes ❑ No

If yes, list allergies:

Do you have seasonal allergies? ❑ Yes ❑ No

If yes, what seasonal allergies do you have?

Do you know how to arrange transportation to your medical appointments? ❑ Yes ❑ No

If no, please talk with your social worker about information on transportation options.

HEALTH CARE PROVIDER INFORMATION

Who is your pediatrician or family doctor?	Phone
Do you see any other doctors? ❑ Yes ❑ No	If yes, what is the name of the doctor?

Why do you see that doctor?

When was the last time you saw a dentist?	Who did you see?

Where do you get your medicines filled?	Phone:	Fax:

Have you had your eyes checked in the past year? ❑ Yes ❑ No

If yes, where did you go?

Were there any problems (such as a need for glasses or sickle cell damage to the eyes) ❑ Yes ❑ No

If yes, describe any problems and the follow-up care needed:

Have you ever received counseling services? ❑ Yes ❑ No	If so, who did you see?	Phone:

PERSONAL HEALTH HISTORY

Have you ever had or currently have one of the following conditions:

Diagnosis	Yes	No	Diagnosis	Yes	No
Acute chest syndrome (pneumonia and one other symptom: cough, fever, shortness of breath)	❑	❑	Hepatitis	❑	❑
Anemia	❑	❑	High blood cholesterol	❑	❑
Asthma	❑	❑	High blood pressure	❑	❑
Avascular necrosis (AVN) (bone damage)	❑	❑	Jaundice (yellow eyes or skin)	❑	❑
Bronchitis	❑	❑	Kidney disease	❑	❑
Cancer	❑	❑	Low blood sugar (Hypoglycemia)	❑	❑
Constipation	❑	❑	Low blood pressure	❑	❑
Diabetes	❑	❑	Mental health treatment	❑	❑
Dizziness	❑	❑	Pain or pressure in chest	❑	❑
Ear infections	❑	❑	Palpitations (rapid beating of the heart)	❑	❑
Eating problems	❑	❑	Periods of unconsciousness	❑	❑
Epilepsy	❑	❑	Pneumonia	❑	❑
Eye problems (other than wearing glasses or contacts)	❑	❑	Priapism (males only): prolonged erection of the penis (2–4 hours)	❑	❑
Fainting	❑	❑	Pulmonary hypertension (high pressures in vessels pumping blood from the heart)	❑	❑
Frequent or severe headaches	❑	❑	Seizures	❑	❑
Gallstones	❑	❑	School problems	❑	❑
Glaucoma (high pressure in the eyes)	❑	❑	Shortness of breath	❑	❑
Hearing problems	❑	❑	Stomach, liver or intestinal problems	❑	❑
Heart condition	❑	❑	Stroke	❑	❑
Hemodialysis	❑	❑	Surgeries (tonsillectomy, splenectomy or other)	❑	❑

If the answer is yes to any of the above conditions, please provide more details about the conditions (examples; describe seizure history, stroke history, surgery history)

BLOOD TRANSFUSTION HISTORY

Have you had a blood transfusion? ❑ Yes ❑ No	If yes, when was the last one?

Did you have ever have a transfusion reaction? ❑ Yes ❑ No

If yes, please describe the reaction:

Are you on chronic blood transfusions? ❑ Yes ❑ No

If yes, why were you put on transfusions?

SICKLE CELL PAIN EVENTS

How often do you have pain from your SCD?

How do you treat your pain?

HOSPITAL EVENT HISTORY

Have you been in the hospital in the last year? ❑ Yes ❑ No

If yes, list when, where, and why you were hospitalized:

HAVE YOU HAD ANY OF THE FOLLOWING TESTS DONE? PLEASE ADD ANY THAT ARE NOT LISTED

Test	Yes	No	Results (if known)	**Doctor/Clinic**
MRI of the brain (takes pictures of the brain)	❑	❑		
CT (takes picture of the body)	❑	❑		
EEG (records brain activity)	❑	❑		
EKG (records heart beats)	❑	❑		
Hemoglobin level	❑	❑	What is your average Hgb?	
Psychological/educational testing (helps determine academic strengths and weaknesses)	❑	❑		
GFR (determines the health of the kidney)	❑	❑		
Echocardiogram (takes pictures of the heart with sound waves)	❑	❑		
Renal ultrasound (takes pictures of the kidneys using sound waves)	❑	❑		

CURRENT MEDICINES

Medicine	What is it taken for?	How much (dose)?	How often is it taken?

IMMUNIZATIONS: HAVE YOU HAD THE FOLLOWING VACCINES?

Type of shot	Yes	No	If yes, what age, (if known)
Hepatitis B	❑	❑	
MMR	❑	❑	
Menactra	❑	❑	
Gardisil (HPV) (females only)	❑	❑	
Varicella (chicken pox)	❑	❑	
Pneumovax	❑	❑	
Influenza (flu)	❑	❑	

LEGAL DOCUMENTS: ADVANCE DIRECTIVE (Please complete this section if you are 17 or 18 years old.)

Do you understand about advance directives? ❑ Yes ❑ No

If yes, have you completed an Advance Care Plan? ❑ Yes ❑ No

Appointment of a Health Care Agent? ❑ Yes ❑ No

Who will be your adult hematologist?

ACADEMIC AND VOCATIONAL INFORMATION

School Name	Highest grade completed?
Do you have an IEP or 504 Plan? ❑ Yes ❑ No	Who is your contact at school?

Are you receiving services from other providers (such as physical or speech therapy)? ❑ Yes ❑ No

Provider	Phone
Provider	Phone

Do you plan to attend college? If yes, where?

Do you have vocational rehab services? ❑ Yes ❑ No	If yes, who is your contact person?

ACTIVITIES OF DAILY LIVING

Please answer the following questions about your activities of daily living.

Question	Yes	No	Does not apply
Do you wear glasses or contacts?	❑	❑	❑
Do you have any hearing problems?	❑	❑	❑
Do you have any speech problems?	❑	❑	❑
Do you have any mobility issues?	❑	❑	❑
Do you use crutches, a walker, or a wheelchair?	❑	❑	❑
Do you have access to transportation?	❑	❑	❑
Do you know how to ride the public bus?	❑	❑	❑
Have you ever scheduled your doctor appointments?	❑	❑	❑
Have you refilled your own prescriptions?	❑	❑	❑
Do you know how to manage your money? (budget, pay bills, etc)	❑	❑	❑
Do you have a photo ID card?	❑	❑	❑

OTHER QUESTIONS?

Are there other questions or issues to discuss that would help you transition to adult care? ❑ Yes ❑ No

Comments: