St. Jude Children's Research Hospital | Department of Hematology

Personal Health Record for Young Adults with Bleeding Disorders

PERSONAL CONTACT INFORMATION		
Last name:	First name:	MI:
Date of birth:		
Street address:		
City:	State:	Zip Code:
Phone number	Cell phone	
Email address:		
Emergency contact	Phone:	Relationship:
Do you have health insurance: ❑ Yes ❑ No		
If yes, give the name of company and policy number (if known):		

HEALTH CARE PROVIDER INFORMATION		
Primary care provider	Name:	Phone #:
Pediatric hematologist	Name:	Phone #:
Adult hematologist	Name:	Phone #:
Dentist	Name:	Phone #:
Pharmacy	Name:	Phone #:
Home health company	Name:	
	Phone#:	Fax #:
Other specialist	Name:	Phone #:
	Specialty:	
Other specialist	Name:	Phone #:
	Specialty:	

PERSONAL HEALTH HISTORY	
Do you have any food or medicine allergies?	❑ Yes ❑ No
If yes, please list and describe reaction symptoms:	

Please list all medicines that you routinely take (both over-the-counter and prescribed):	
Medicine name/dose	Reason for taking medicine:
Immunizations: Do you know if your vaccinations are up-to-date?	❑ Yes ❑ No
Have you been vaccinated against Hepatitis A (2 shots series)?	❑ Yes ❑ No
Have you been vaccinated against Hepatitis B (3 shot series)?	❑ Yes ❑ No
Do your hepatitis serologies show that you are protected against Hepatitis?	❑ Yes ❑ No ❑ Unsure
(Please ask your hematologist for the date of your last serologies)	Date:

Surgical history	
Dates	Procedure

Hospitalization history	
Dates	Reason

Have you ever had or currently have one of the following conditions:					
Diagnosis	Yes	No	Diagnosis	Yes	No
Anemia	❑	❑	Hepatitis	❑	❑
Blood in your stool	❑	❑	High/low blood pressure	❑	❑
Blood in your urine	❑	❑	HIV	❑	❑
Central venous line	❑	❑	Inhibitor	❑	❑
Easy bruising	❑	❑	Kidney disease	❑	❑
Frequent or severe headaches	❑	❑	Mental health disorder (ADD, ADHD, bipolar, depression)	❑	❑
Gingival (gums) bleeding	❑	❑	Nosebleeds	❑	❑
Head/spinal injury or bleed	❑	❑	Severe bleeding event	❑	❑
Heart condition	❑	❑	Target joints	❑	❑
If the answer is yes to any of the above conditions, please provide more details about the conditions:					

BLEEDING DISORDER SPECIFIC:

1. What type of bleeding disorder do you have?	❑ Factor VIII Deficiency	❑ Factor IX Deficiency	❑ von Willebrand Disease	❑ Other:
2. Do you know your average factor VIII/IX level?	%	❑ Mild ❑ Moderate ❑ Severe		
3. Have you ever had an inhibitor?	❑ Yes ❑ No			
If yes, did you undergo Immune Tolerance Induction (ITI)?		When?	Was it a success?	
4. Factor Infusions				
Factor replacement product:				
Factor is infused through:	❑ Peripheral IV access	❑ Central venous line (CVL)	Date of CVL placement:	
Factor is infused by:		Can you self-infuse? ❑ Yes ❑ No		
Are you on prophylactic dosing?	❑ Yes ❑ No			
If yes, what is your dosing schedule? Please check the days of the week that you infuse:				
❑ Sunday ❑ Monday ❑ Tuesday ❑ Wednesday ❑ Thursday ❑ Friday ❑ Saturday				
How many units do you infuse per dose?				
Do you understand the treatment plan guidelines for on-demand bleeds?	❑ Yes ❑ No			
Where is this information kept?				
5. Target Joints: Do you have any known target joints? Please check all that apply:				
❑ Left ankle ❑ Right ankle ❑ Left knee ❑ Right knee ❑ Left elbow ❑ Right elbow				
Have your target joints been confirmed with diagnostic imaging?	❑ Yes ❑ No			
If yes, where were the studies completed?				
6. Acute Bleeds				
How do you know that you are having a bleed?				
How do you treat your bleeds?	Mild	Moderate/joint bleed		
Severe				
Closest medical facility in the event of an emergency or trauma:				
Does this emergency department have factor replacement products available?	❑ Yes ❑ No ❑ Unsure			

FAMILY HISTORY: (please include any family history of bleeding disorders, platelet disorders, inhibitors, etc)

ACTIVITIES OF DAILY LIVING:		
	Yes	No
Do you have any mobility issues?	❑	❑
Do you use crutches, walker, or a wheelchair?	❑	❑
Do you require any special accommodations?	❑	❑
Do you have access to transportation?	❑	❑
Have you ever scheduled your doctor appointments?	❑	❑
Have you ever called a pharmacy to request a medicine refill?	❑	❑

OTHER RESOURCE INFORMATION			
School name			Highest level or grade completed?
	Yes	No	
Do you have an IEP or 504 Plan?	❑	❑	School contact:
Do you have vocational rehab services?	❑	❑	Contact person:
Are you receiving SSI/Disability benefits?	❑	❑	
Are you receiving food stamps (SNAP) or Families First?	❑	❑	
If yes, who is your Department of Human Services (DHS) worker?			
Are you now or have you ever received counseling services?	❑	❑	
If so, who is the provider?			Phone:

LEGAL DOCUMENTS AND ADVANCE DIRECTIVES (18 YEARS OF AGE AND OLDER)			
	Yes	No	
Do you have an advance directive?	❑	❑	
If yes, Advanced Care Plan?	❑	❑	
Appointment of health care agent?	❑	❑	
If you have a health care agent, who is it?			Phone:

For clinic use only			
✓		✓	
	Sign release of information prior to transitioning		Referrals made (PT/OT)
	Infusion training provided, if needed for self-infusions		New treatment plan faxed to home health company and copy given to family
	Travel letter provided		Evaluate for any known upcoming dental or surgical procedures
	Final clinic note mailed to adult provider		Genetic counseling completed