



**Innovative  
Hematology**

Indiana Hemophilia  
& Thrombosis Center

# MY ADVENTURES WITH **Blood Clots**





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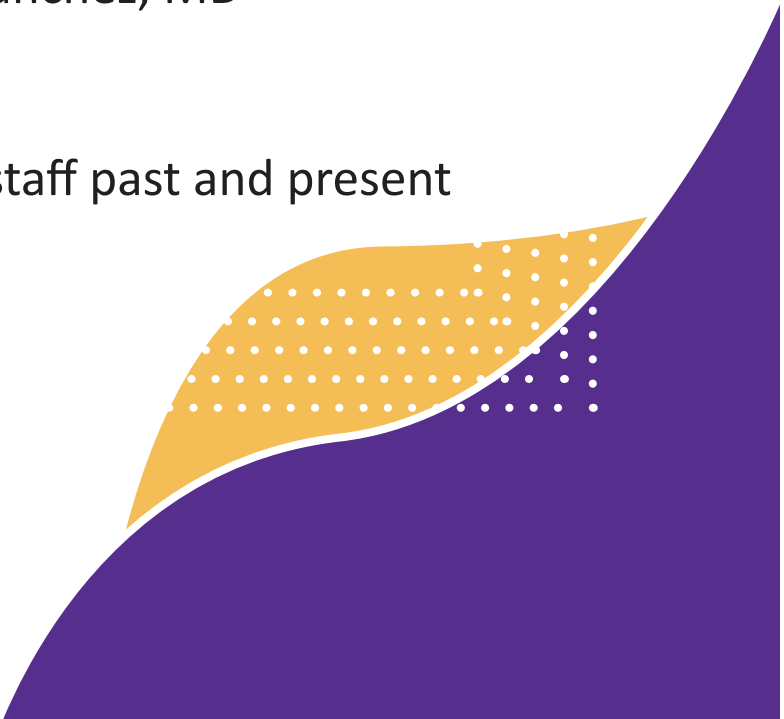
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**Special thanks to:**

Innovative Hematology staff past and present

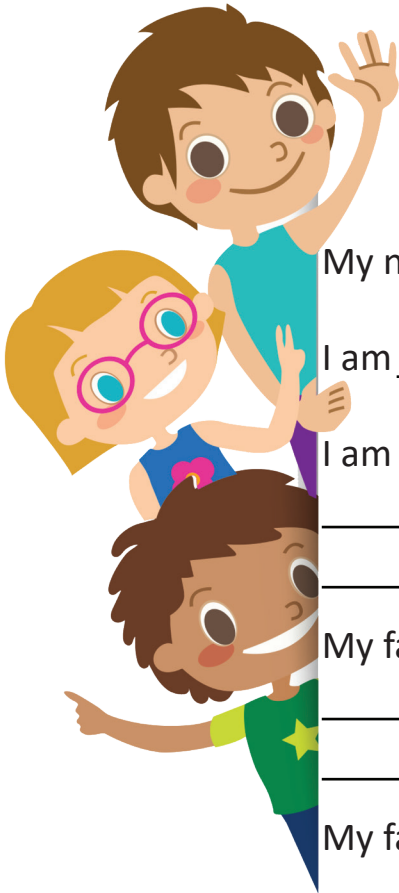


# Welcome To Innovative Hematology

This book is for kids like you, who are patients of Innovative Hematology. You visit Innovative Hematology because you are a kid living with, are at risk for, or have had a blood clot (thrombosis) in your body. This book was made by your Innovative Hematology team to help you learn about Innovative Hematology and blood clots. This is YOUR book; you can draw and write in it and take it home with you!



# My Page



My name is \_\_\_\_\_

I am \_\_\_\_\_ years old.

I am from \_\_\_\_\_

My favorite things about me are \_\_\_\_\_

My family members are \_\_\_\_\_

When I grow up I want to be a \_\_\_\_\_





# My Care Team



## Doctor

The doctor is in charge of your care. They see you in the clinic and ask how you are feeling and answer your questions about your blood or blood clots.



## Physician Assistant/ Nurse Practitioner

The physician assistant/nurse practitioner works with the doctor and may see you in the clinic. They ask questions about the things you do and your pain, to understand how you are feeling.



## Clinic Nurse

The nurse checks you into your room. They check your height, weight, temperature and blood pressure. They may ask about your medicine, when you take it and how much.



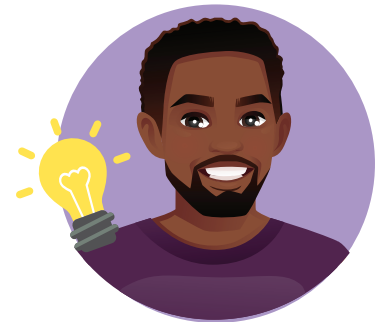
## Thrombosis Coordinator

The thrombosis coordinator will see you at your appointment. They teach you and your family about blood clots and how your blood works.



## School/Career Counselor

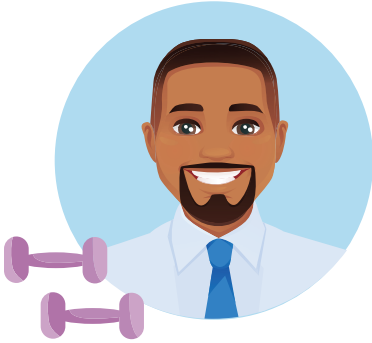
The school/career counselor may see you in clinic. They can teach you and your family about how to talk to others about your blood clot. Sometimes they visit your school to teach your teachers and the school nurse about your blood clots.



## Child Life Specialist

The child life specialist helps you understand your blood clot and the things done in clinic. They can help you find things to do when you are feeling scared to help you feel better.

# My Care Team



## Physical Therapist

The physical therapist may see you in clinic. Sometimes they take measurements of your arms and legs or where your blood clots were. Don't worry, it doesn't hurt at all.



## Dental Hygienist

A dental hygienist may meet with you and your parents in the clinic and talk with you about brushing your teeth. They will talk to you about going to the dentist and taking your medicine. They will teach you how to brush and things to watch for if you are taking medicine for your blood clot.



## Research Nurse

The research nurse may meet with you and tell you about how you can help Innovative Hematology. One way in which you can help us learn more about blood clots is called a study. By learning about you, we can help lots of people who have blood clots.



## Triage Nurse

The triage nurse is who you would talk to if you or your family called Innovative Hematology. They are really good at answering questions about blood clots. They talk to your doctor to see if you need to come to clinic for a visit.



## Dietitian

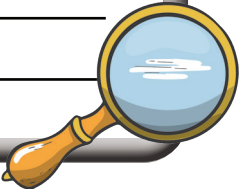
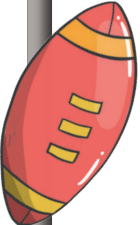
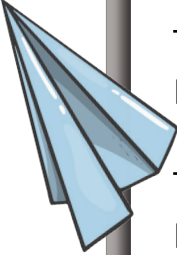
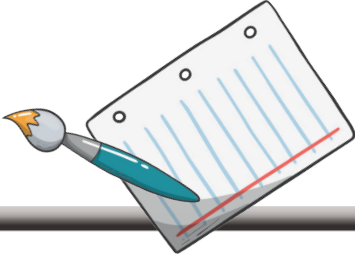
A dietitian may meet with you and your parents in the clinic and talk with you about the foods that you like to eat. They will teach you what foods have a lot of vitamins and are good for you. They will also teach you about the types of foods you should be eating to grow big, strong, and healthy.



## Genetic Counselor

The genetic counselor may see you in clinic and ask you and your family about your whole family. They want to find out if anyone in your family has had any blood clots like you.

# My Favorite Things



My favorite television show is \_\_\_\_\_

My favorite place is \_\_\_\_\_

My favorite team is \_\_\_\_\_

My favorite color is \_\_\_\_\_

My favorite things to do are \_\_\_\_\_



# What You Should Know About Me

When I am happy, I like \_\_\_\_\_

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When I am scared, I want \_\_\_\_\_

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When I hurt, it is hard to \_\_\_\_\_

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I am great at \_\_\_\_\_

---

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Some other things I want you to know about me are \_\_\_\_\_

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# What You Should Know About School

Where I go to school: \_\_\_\_\_

What grade I am in: \_\_\_\_\_

The best thing about school is \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

The worst thing about school is \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What I am good at in class: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What is hard for me in class: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Here is a picture of me in class:



# Blood Clots Can Be Called Thrombosis

I know that is a BIG word. It means your blood doesn't always work the way it is supposed to. For some kids, their blood makes too many clots and sometimes those clots get stuck together and that makes a bigger clot called thrombosis. Sometimes blood clots can happen after being in the hospital, after being hurt, and sometimes all on their own. Blood clotting disorders are sometimes passed to you from your family members. This makes it easier for you to get a blood clot.

**Do you know if any of your family members have had blood clots like you?**



# Most Common Blood Clotting Disorders

Antithrombin III Deficiency

Factor Five Leiden

Prothrombin Gene Mutation

Antiphospholipid Antibody Syndrome

Protein C Deficiency

Protein S Deficiency

Do you have any of these blood clotting disorders?

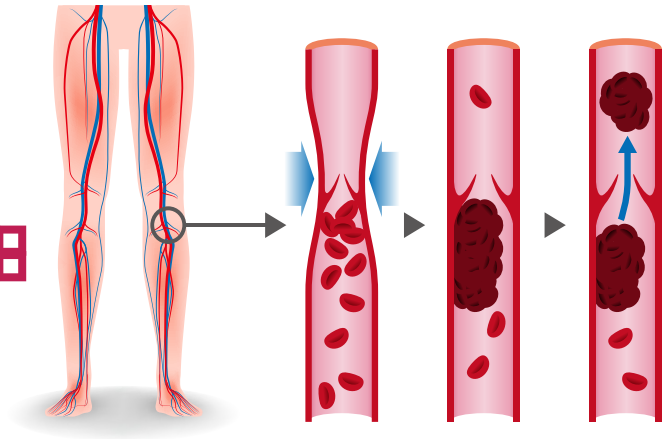
Do you know which one? Circle from the list above.



# Types Of Blood Clots You Can Have:

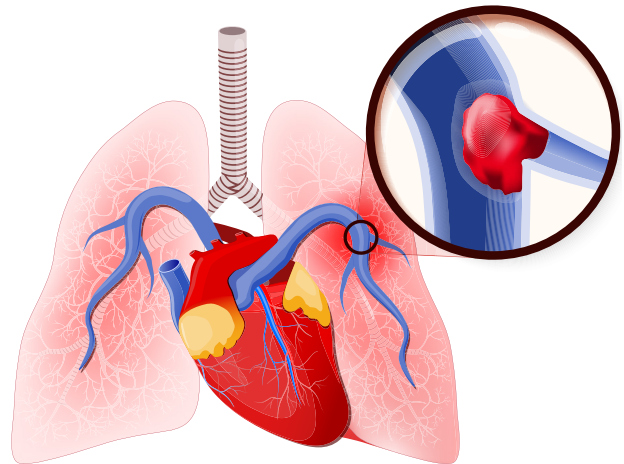
## Deep Vein Thrombosis (DVT):

are common in the arms or legs, but can be in other veins too.



## Pulmonary Embolism:

are found in the lungs.

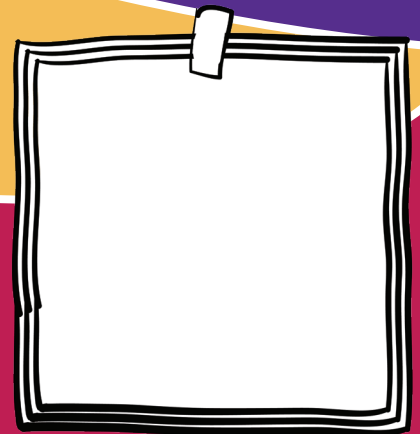
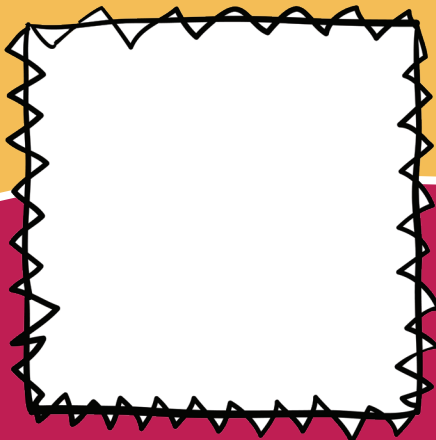
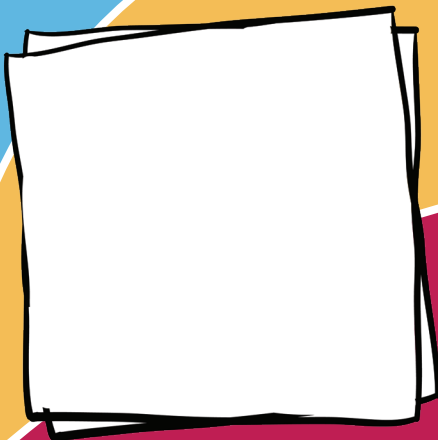
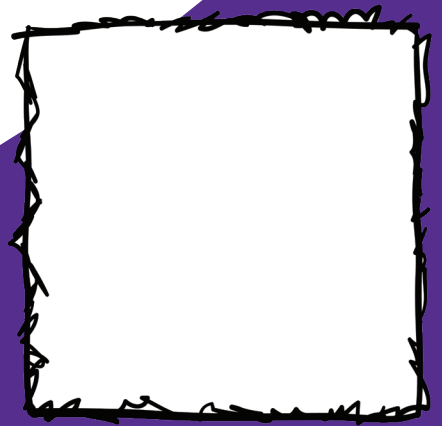
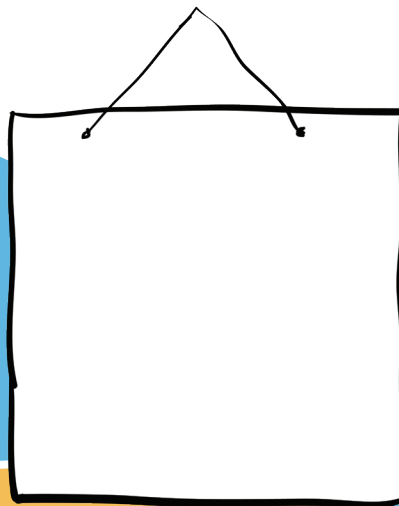
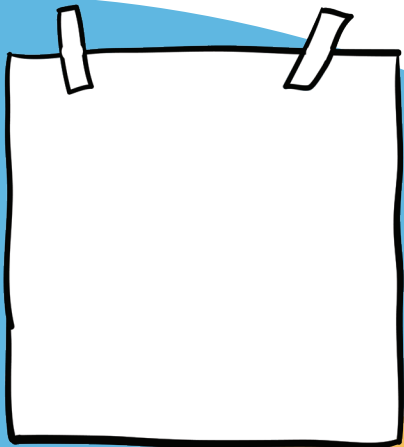
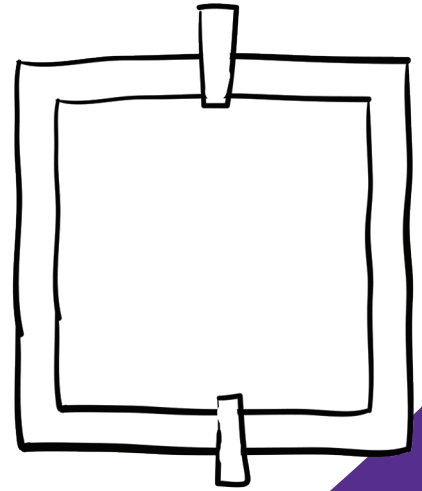
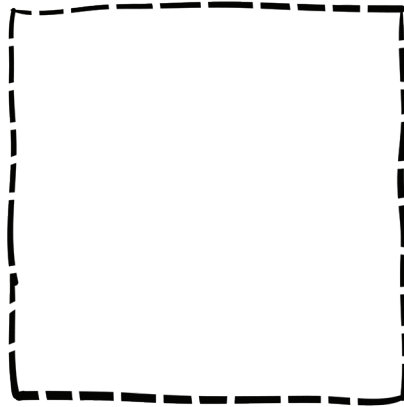
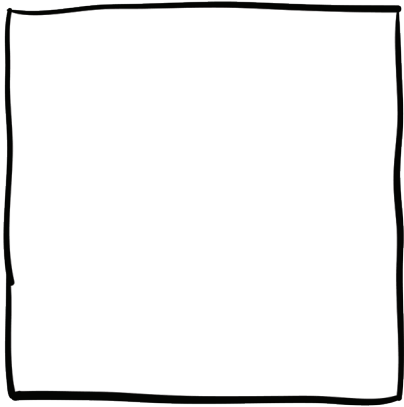


## Cerebral Sinus Venous Thrombosis:

is found in the head.



# This Is What I Think My Blood Clots Look Like:

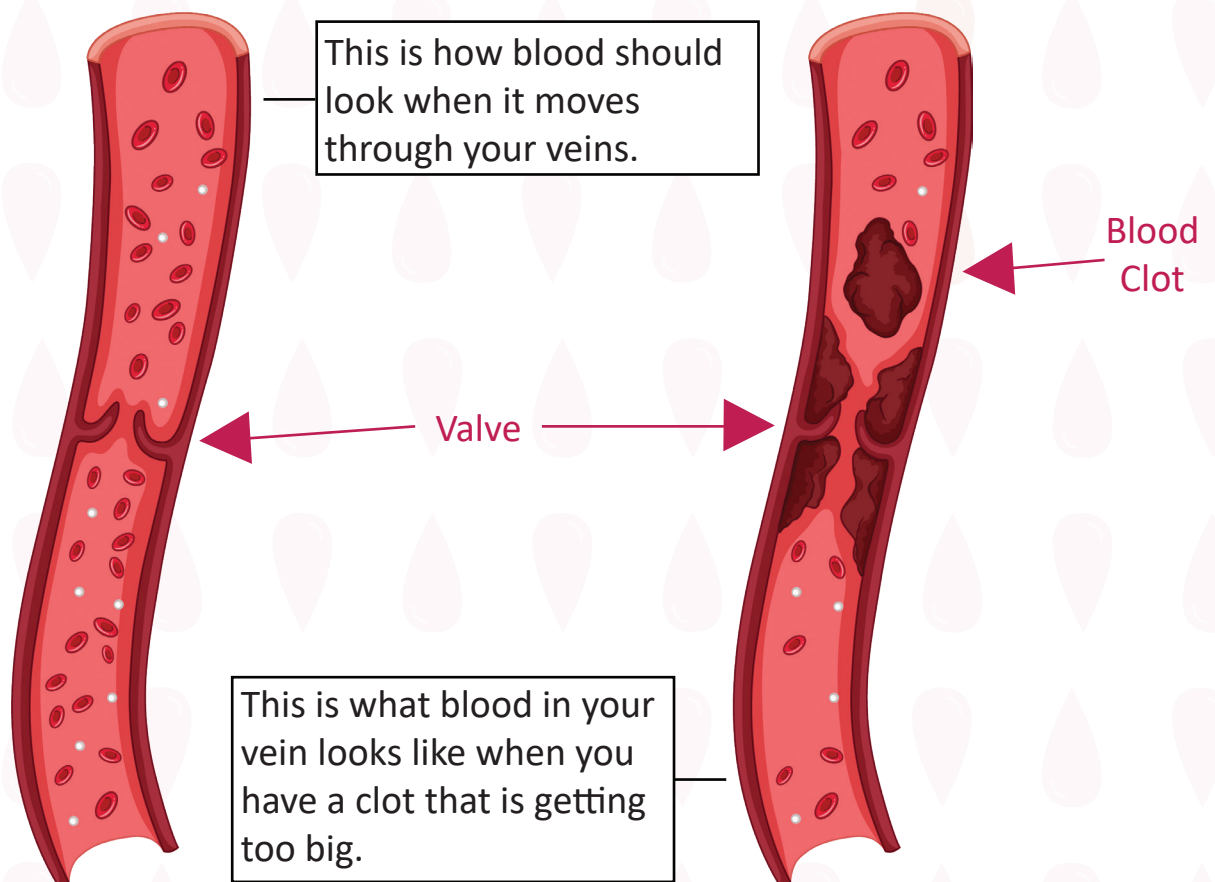


# Things To Know About Blood...

Everybody makes blood clots. They help us stop bleeding when we get hurt. Blood clots are made up of different parts of your blood.

- Platelets—are like stickers. They stick to the area that is hurt.
- Plasma—is the watery part of your blood that helps things move around.
- Clotting Factors—help make the platelets sticky.

Sometimes your blood gets clotted in a vein. It can sometimes make that part of your body hurt and turn red and maybe swell up (get big and puffy). This happens because the blood can't move through the vein like it is supposed to. It's kind of like a traffic jam in your vein.



# How Do You Know I Have A Blood Clot?

You need a scan (a picture made by a machine) to know if you have a blood clot. There are different types of scans that can help see your blood clot better.

Have you ever had a scan?

Do you know what kind of scan you had?

Match the following pictures with the correct name and description. *Flip the page upside down to see the answers under the machines.*



Ultrasound



CT Scan



MRI

**Computed Technology Scan (CT Scan)** - is a scan that uses computers and x-ray to give a very detailed picture of the inside of your body. With this scan the machine moves around you to take the pictures it needs. You lie on a bed. This type of scanning machine also looks like a big doughnut.

**Magnetic Resonance Imaging (MRI)** - is a scan that uses a big magnet to take pictures of the inside of your body. An MRI doesn't touch you, but it is very important to hold very still while the MRI is taking pictures. Sometimes the MRI machine can look scary (it looks like a big doughnut). It can take a long time to get an MRI and it can be loud.

**Ultrasound (US)** - uses jelly on a really cool wand to show the inside parts of your body on a computer screen. The jelly can sometimes feel cold and wet. You may feel the wand touch you but it doesn't hurt.



# Things That Help Your Blood Clot Get Better

Fill in the blanks with the following words:

medicines

blood

clot

bigger



If you have a blood clot or had a blood clot before, it is important to talk to your doctor. They can help you know what medicine will keep your blood clot from getting \_\_\_\_\_.

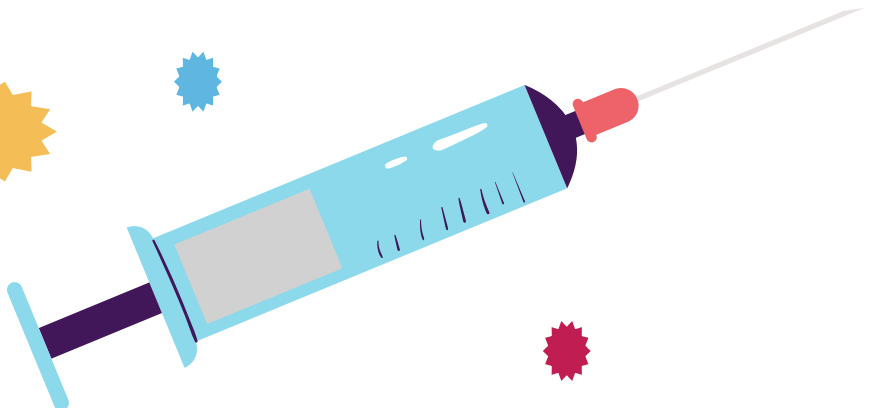
Blood clots sometimes need \_\_\_\_\_ that only come as injections. This medicine is given with a small needle. These injections are given in the arm, leg or stomach where your skin is a little more squishy.

Did your blood clot need injections?

Other times \_\_\_\_\_ clots need medicines that come in pills and need to be swallowed.

Sometimes your blood clot needs injections for a little while and then pills to get smaller. These medicines are called blood thinners.

If you have a blood \_\_\_\_\_ in your arms or legs sometimes the doctor wants you to wear a tight sleeve or sock called a compression garment. These are used to help with pain and swelling.



# Could I Get Another Blood Clot?

If you have had a blood clot before or have taken medicine for a blood clot, it is important to watch for any of these signs.

- Swelling (big and puffy) in your arms and legs—Does one look bigger than the other?
- Places in your arms and legs that hurt and the pain doesn't go away
- Changes in the color (red, blue, purple) of your skin on your arms or legs
- Changes in your eye sight—things looking blurry
- Feeling like it is hard to breathe, your chest hurts, or your spit is red
- Dizziness (your head feels funny or things look like they are spinning)
- Nose bleeds, blood in your poop or pee if you are taking medicine for a blood clot
- Any cuts or scrapes that don't stop bleeding if you are taking medicine for a blood clot

If you have any of these...

**YOU SHOULD:**

**Tell  
Someone**

**Go to the  
Hospital**

**1-800-CLOTTER**

**Call  
Innovative  
Hematology**

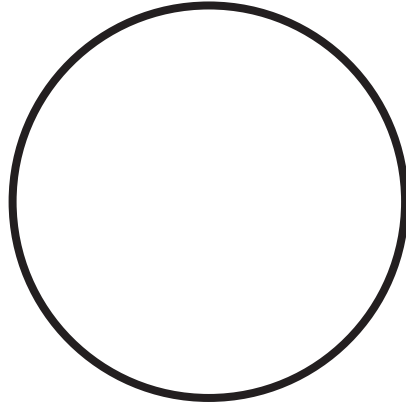


# My Feelings

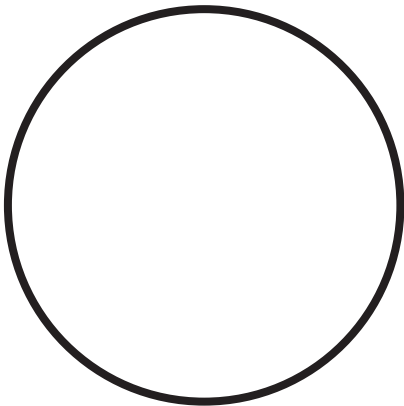
When I think about my blood clot some of the feelings I have are:



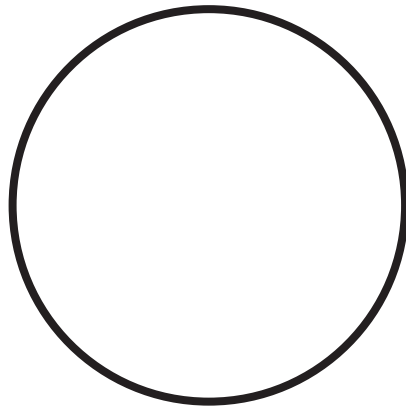
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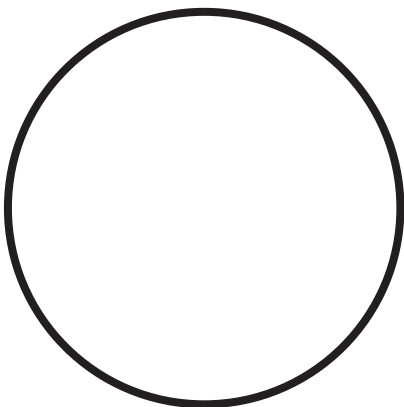
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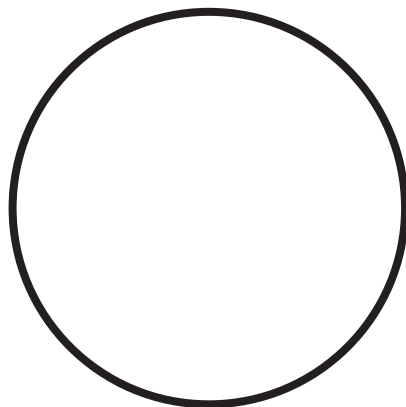
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# Who Should I Tell If I Get Hurt?

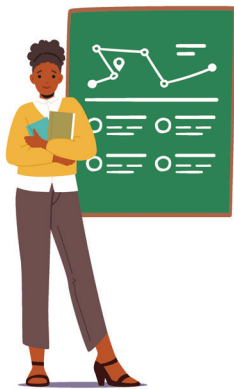
If you are on a medicine for a blood clot, it is very important to tell someone if you get hurt. You should let an adult know, especially if you fall, hit your head, neck or stomach. You should also tell someone if you have pain or swelling in your arms or legs. You should tell someone as soon as possible even if you are at school or at a sports practice. Your teachers and coaches can help you call your family and call Innovative Hematology to see if you need to see a doctor.

Who would you tell if you were at home? \_\_\_\_\_

\_\_\_\_\_

Who would you tell if you were at school? \_\_\_\_\_

\_\_\_\_\_



# Things YOU Can Do That Help Your Blood Clot Get Better

Drink Lots of Water

Exercise

Take My Medicine

Eat Healthy

Rest

Wear My Compression Garment





**Draw a picture of the sports and activities you like to play.**

It is important to tell your coaches or gym teacher if you are taking any medicine for your blood clot. When you play sports and do activities, there are more chances for you to get hurt. This is true even for sports you do on your own like swimming and running. If you need to take medicine for your blood clot you may need to wait on doing some activities. Your doctor will help you and your family understand what activities you can do.

# Put Me In Coach

If you are taking medicine for a blood clot, it is very important to keep your emergent care anticoagulation card with you at all times. It is small and will easily fit in your backpack. It lets people know important things about you and your blood clot - like your name, birthday, and if you use any kind of medicine for your blood clot. Your emergent care card tells people that they need to do something if you get hurt. No matter where you are, what you are doing, or who you are with, you should ALWAYS have your emergent care card with you.

# My Emergent Care Card

What Information is on your emergent care card?

|                                                                                                                  |  |
|------------------------------------------------------------------------------------------------------------------|--|
| <b>Emergent Care Card</b>                                                                                        |  |
| <b>ANTICOAGULATION</b>                                                                                           |  |
|  <b>Innovative Hematology</b> |  |
| <b>1-877-256-8837</b>                                                                                            |  |

|                                                                                                                                    |                  |
|------------------------------------------------------------------------------------------------------------------------------------|------------------|
| Patient Name _____                                                                                                                 |                  |
| Date of Birth _____                                                                                                                | Blood Type _____ |
| Medication & Dose _____                                                                                                            |                  |
| Reason for Anticoagulation _____                                                                                                   |                  |
| Prescribing Physician _____                                                                                                        |                  |
| <b><i>Patient may be at risk for severe bleeding.</i></b><br><i>Please call the center for specific treatment recommendations.</i> |                  |

# Things I've Learned at Innovative Hematology

Circle the words you see below

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| E | G | E | X | E | B | G | S | M | P | I | Q | N | R | B |
| W | V | B | M | B | S | E | W | Q | T | Z | M | O | P | K |
| Y | G | O | M | Z | J | I | T | Z | Y | O | K | I | L | V |
| F | T | K | M | H | D | B | C | S | Q | X | X | S | A | F |
| K | Q | T | N | K | Q | L | E | R | B | P | D | S | T | O |
| N | D | L | C | J | E | O | E | U | E | O | K | E | E | S |
| J | S | L | R | L | G | O | T | T | C | X | I | R | L | M |
| P | O | R | U | L | V | D | Z | T | C | H | E | P | E | W |
| T | J | W | A | T | E | R | O | L | H | E | Z | M | T | V |
| X | Y | Q | C | O | H | R | J | I | V | A | D | O | K | C |
| L | Y | G | O | V | A | Q | Z | Q | O | C | K | C | T | X |
| S | I | S | O | B | M | O | R | H | T | U | E | H | N | O |
| E | N | I | C | I | D | E | M | L | G | V | I | L | G | Z |
| O | D | M | C | Q | Q | A | F | J | Z | K | F | Y | L | K |
| N | F | Q | K | E | J | O | B | W | Y | Q | D | G | Q | Q |

~~Blood~~  
Compression  
IHTC  
Platelet

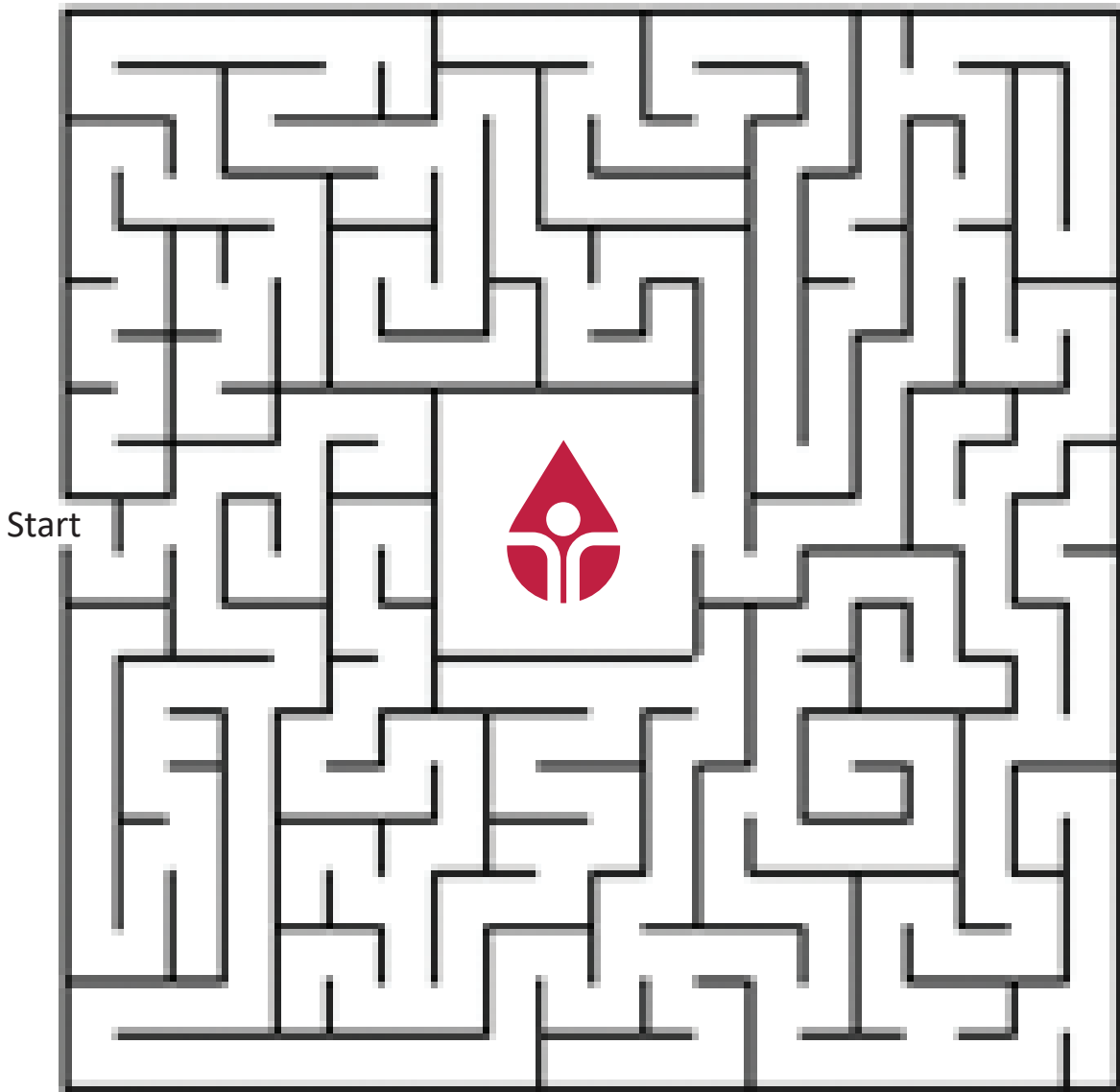
Cell  
Doctor  
Medicine  
Thrombosis

Clot  
Exercise  
Move  
Water

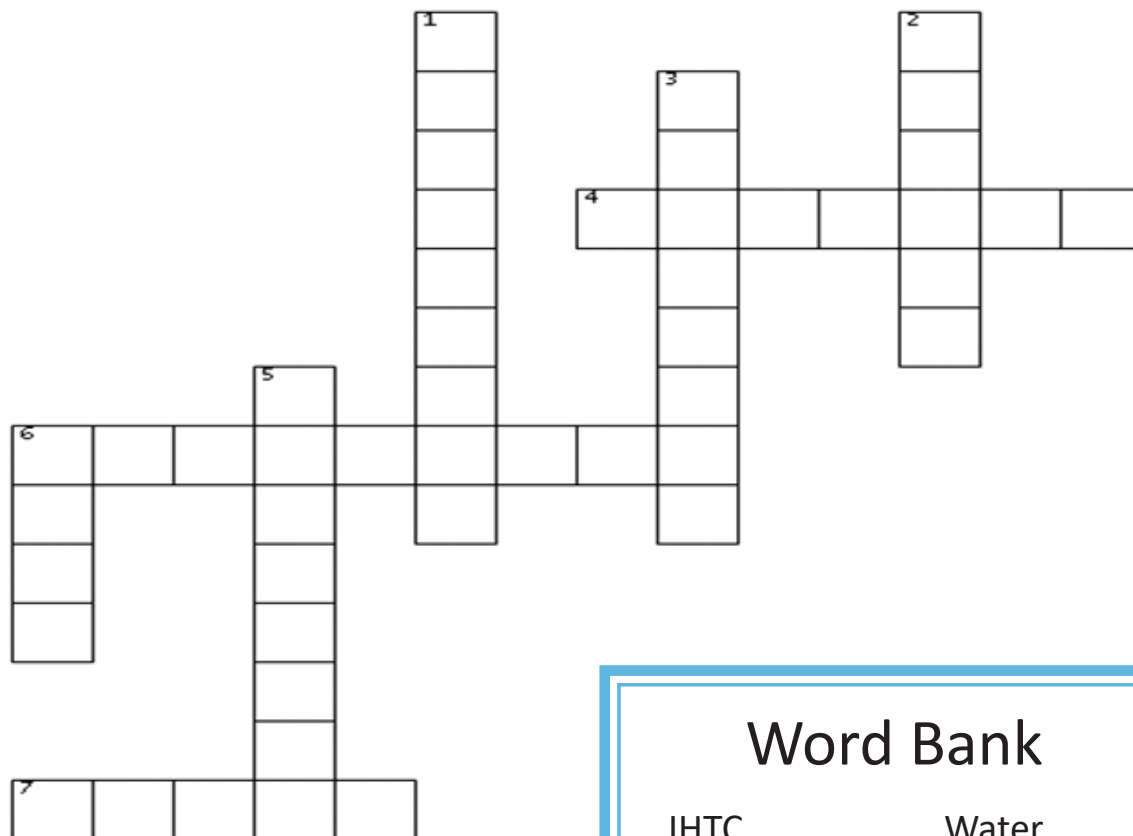
# Innovative Hematology...

## What A Place!

Innovative Hematology is a big place and lots of things happen here; it can be confusing! See if you can make it through the Innovative Hematology maze to the finish.



Fill in the blanks



## Word Bank

|           |           |
|-----------|-----------|
| IHTC      | Water     |
| Injection | Doctor    |
| Healthy   | Platelets |
| Medicine  | Swelling  |

### ACROSS

4. What kind of meals should you eat every day?
6. This is one type of medicine that can help blood clots get smaller.
7. You should drink lots of \_\_\_\_?

### DOWN

1. What helps your blood clot?
2. This person helps you get better and may give you medicine to help your blood clot get better.
3. When your arm or leg is puffy or bigger than the other one.
5. Don't forget to take \_\_\_\_?
6. What do we call Indiana Hemophilia & Thrombosis Center?



# Innovative Hematology

## **Why do I have to come here?**

The clinic wants to make sure you are feeling well and that you don't need any changes in your medicine. They also want to make sure your blood clot is not causing you any problems.

## **Why do I have to have blood draws?**

The clinic needs to check your blood to make sure your medicine is working and to see if you need a different amount of medicine.

## **Why do I have to take medicine?**

To help keep your blood clot from getting bigger. It is important to take all of your medicines so that they can do their best work for you.

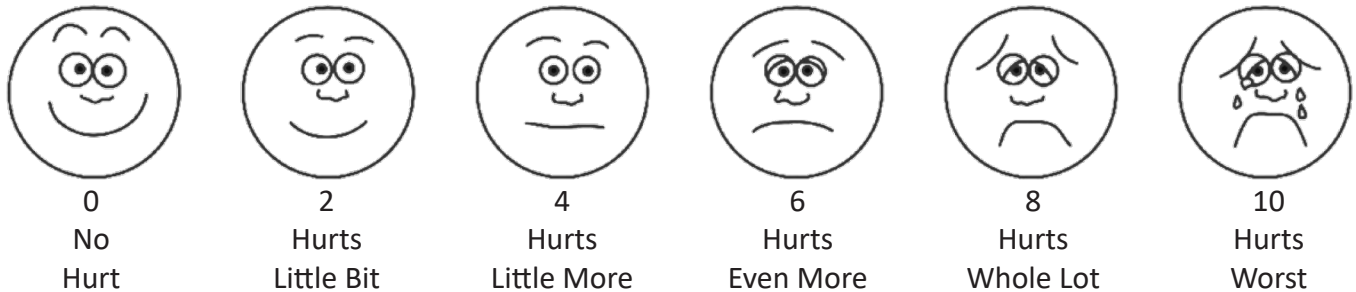
## **Can people get a blood clot from me?**

No, people can not get a blood clot from you. Blood clotting can be passed down in your family. Do you know anyone else in your family that has had a blood clot?



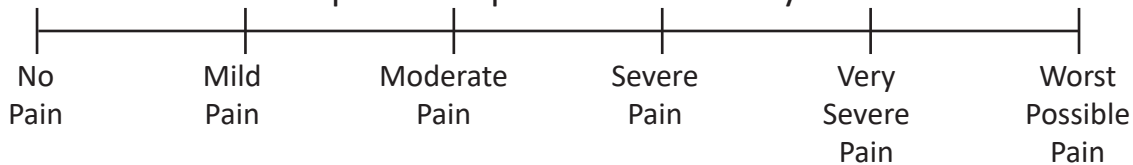
# Pain Scales

Wong-Baker FACES™ Pain Rating Scale

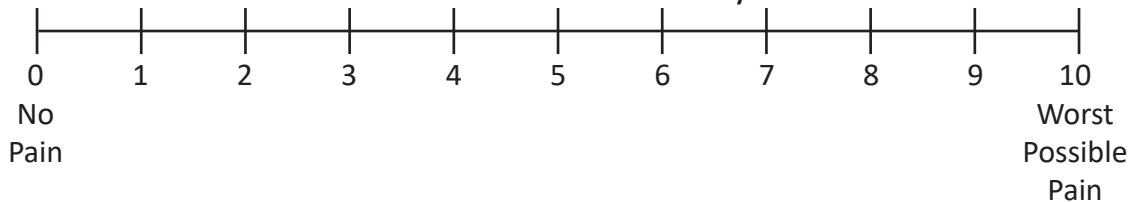


©1983 Wong-Baker FACES™ Foundation. Used with permission.

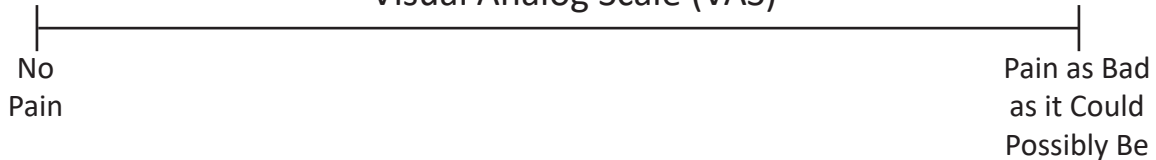
Simple Descriptive Pain Intensity Scale<sup>1</sup>



0-10 Numeric Pain Intensity Scale<sup>1</sup>



Visual Analog Scale (VAS)<sup>2</sup>



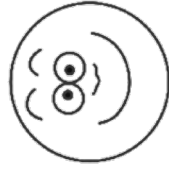
<sup>1</sup> If used as a graphic rating scale, a 10 cm baseline is recommended

<sup>2</sup> A 10-cm baseline is recommended for VAS scales.

## Pain Tracking Chart

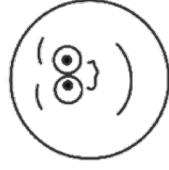
Keep track of how you are doing.

### Wong-Baker FACES™ Pain Rating Scale



0

No Hurt



2

Hurts  
Little Bit



4

Hurts  
Little More



6

Hurts  
Even More



8

Hurts  
Whole Lot

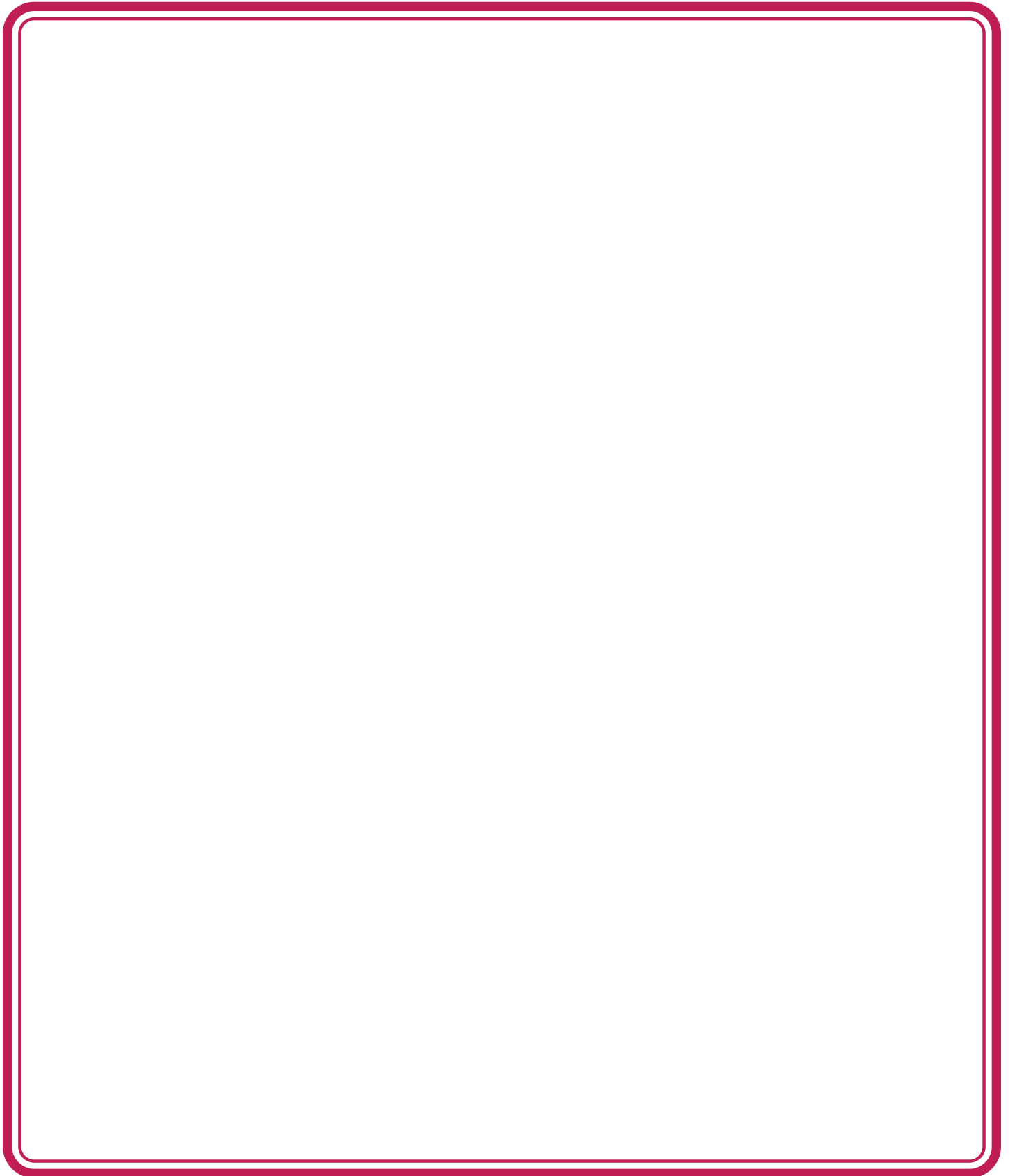


10

Hurts Worst

|       |       |                    |                                               |
|-------|-------|--------------------|-----------------------------------------------|
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |
| Date: | Time: | Location of Pain:  | What did you do to help yourself feel better? |
|       |       | Pain Scale Rating: |                                               |

# Autographs

A large, empty rectangular box with a double red border, intended for an autograph.

**You're a  
STAR!**

