



The Force for Health®
PREPARED PATIENT PROGRAM

PREPARED PATIENT

Sickle Cell Disease

Your complete learning module — eight components from newly-diagnosed to a clinically Prepared Patient Ambassador. Everything to know and do, in one place.

8-Component Condition Module

WHAT'S INSIDE — THE 8 COMPONENTS

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| 1 Core Basics | 2 Self-Reflection |
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SCAN TO OPEN THE
LIVE JOURNEY

1 Core Basics

Welcome — why becoming a Prepared Patient matters

Welcome. You're in the right place. This module turns Sickle Cell Disease from something that happens *to* you into something you help manage — step by step, at your own pace. You don't need to become a doctor. You need to become the most prepared person in the room about *your* health.

WHY THIS MATTERS — FOR YOU AND THE PEOPLE AROUND YOU

As a Patient

Know your numbers, spot your red flags, and act fast when it counts. Prepared patients have better days and fewer emergencies.

As an Ambassador

Speak up in your own care as an equal partner — ask the right questions and help shape your plan.

As a Caregiver

Support someone you love with confidence — know what to watch for and what to do.

SICKLE CELL DISEASE — A NATIONAL OVERVIEW

Sickle Cell Disease (SCD) runs in families. It affects your red blood cells. A small change in one gene changes your hemoglobin. Hemoglobin is the part of a red cell that carries oxygen.

This change makes hemoglobin S. Some things stress your cells. These include low oxygen, not enough water, cold, and infection. Under stress, hemoglobin S clumps together.

It bends red cells into stiff, curved shapes. These sickle cells get stuck in small blood vessels. That leads to pain, organ damage, low blood counts, and infections.

But care today is strong. It includes hydroxyurea (a daily pill), shots to prevent infection, blood transfusions (getting healthy blood), and newer drugs.

A bone marrow transplant or gene therapy may even cure SCD. Most people with SCD now live longer, fuller lives.

PRE-KNOWLEDGE CHECK — RATE WHAT YOU KNOW RIGHT NOW (1–5)

Be honest — there's no wrong answer. You'll rate these again at Step 7 and see how far you've come.

What Sickle Cell Disease actually is

○ ○ ○ ○ ○

My key numbers & targets

○ ○ ○ ○ ○

My red flags — and what to do

○ ○ ○ ○ ○

My medicines & how to take them

○ ○ ○ ○ ○

How to speak up with my care team

○ ○ ○ ○ ○

1 = new to me · 5 = I could teach it



1 Core Basics

Welcome — why becoming a Prepared Patient matters

★ My Prepared Patient Pledge

I pledge to learn about my Sickle Cell Disease, to know my numbers and my red flags, to speak up in my own care, and to take one small step at a time — for myself and for the people who count on me.

SIGNED

DATE

Additional Notes

☐ I've completed Step 1 · Welcome & Overview for Sickle Cell Disease



2 Self-Reflection

Eight soft questions to find your honest starting point

No test, no wrong answers — an honest self-reflection to find your starting point with Sickle Cell Disease. This is an engagement screener, not a clinical assessment. Mark your answers, then carry them into the Fact Sheet.

Q1 Have you actually been tested for sickle cell trait or sickle cell disease?

This is the first thing many families never know to ask.

CHOOSE ONE

- ☐ Yes — I have sickle cell disease
- ☐ Yes — I carry the sickle cell trait
- ☐ Yes — I tested negative
- ☐ No, I haven't been tested
- ☐ I'm not sure / I don't remember

Q2 Has anyone in your family been diagnosed with sickle cell, or known to carry the trait?

Family awareness is one of the most useful pieces of context for SCD.

CHOOSE ONE

- ☐ Yes
- ☐ No
- ☐ I don't know
- ☐ Some, but I'm not sure who

Q3 Have you ever heard about, or experienced, any of these in connection with sickle cell? (check all that feel familiar)

This is just a familiarity check, not a symptom audit. Pick whatever rings a bell.

CHECK ALL THAT APPLY

- ☐ Episodes of severe pain ("pain crises")
- ☐ Anemia or chronic fatigue
- ☐ Being hospitalized for sickle cell
- ☐ Newborn screening for SCD
- ☐ Hydroxyurea, transfusions, or gene therapy
- ☐ None of these — this is all new to me



2 Self-Reflection

Eight soft questions to find your honest starting point

Q4 Do you feel confident that you understand sickle cell — what it is, what it does to the body, and what helps?

"Somewhat" is a totally fair answer. Most people start there.

CHOOSE ONE

- ☐ Very confident — I know the basics well
- ☐ Somewhat — I know some, want to know more
- ☐ Not really — I'd like to learn more
- ☐ This is new to me

Q5 Do you feel confident you know how to live the highest-quality life possible despite SCD — for yourself, or for someone you love?

Quality of life is the goal, not just "managing the disease."

CHOOSE ONE

- ☐ Yes
- ☐ I'm getting there
- ☐ Not yet — I want to learn how
- ☐ Not applicable to me right now

Q6 Are you ready to become an informed and respected part of your care team — where your observations, communications, and actions are the most important part of your care?

This is the heart of the Prepared Patient idea.

CHOOSE ONE

- ☐ Yes — I'm ready
- ☐ Almost — I want to learn more first
- ☐ I'd like to but I'm not sure how
- ☐ I hadn't thought of it that way before



2 Self-Reflection

Eight soft questions to find your honest starting point

Q7 Do you have at least one person — family, friend, or care team — you can turn to about sickle cell?

Knowing your circle matters as much as knowing your meds.

CHOOSE ONE

- ☐ Yes — I have someone
- ☐ Maybe — I'm not sure who
- ☐ Not yet — but I'd like to find someone
- ☐ I prefer to figure it out myself first

Q8 What brought you to this Prepared Patient program today?

Your answer is private and helps us speak to you better.

CHOOSE ONE

- ☐ I have SCD
- ☐ Someone I love has SCD
- ☐ I might have SCD or carry the trait
- ☐ I'm a friend or community member
- ☐ I'm a student, professional, or educator
- ☐ I'm just curious

What these answers tell me about where I'm starting



2 Self-Reflection

Eight soft questions to find your honest starting point

Additional Notes

☐ I've completed Step 2 · Self-Reflection for Sickle Cell Disease



3 Force Field Fact Sheet

Primer · Foundations

This is the heart of the resource: the complete Sickle Cell Disease Force Field, organized in knowledge tiers. Each card gives the essentials, then **Concepts** (what to know), **Skills** (what you can do), **Actions** (this week), and your **Plan** (share & sustain).



What Is Sickle Cell Disease?

PRIMER · TIER 0

Sickle Cell Disease (SCD) runs in families. It affects your red blood cells. A small change in one gene changes your hemoglobin. Hemoglobin is the part of a red cell that carries oxygen.

This change makes hemoglobin S. Some things stress your cells. These include low oxygen, not enough water, cold, and infection. Under stress, hemoglobin S clumps together.

It bends red cells into stiff, curved shapes. These sickle cells get stuck in small blood vessels. That leads to pain, organ damage, low blood counts, and infections.

But care today is strong. It includes hydroxyurea (a daily pill), shots to prevent infection, blood transfusions (getting healthy blood), and newer drugs.

A bone marrow transplant or gene therapy may even cure SCD. Most people with SCD now live longer, fuller lives.

CONCEPTS · LEARN IT

- SCD runs in families. You are born with it. It is not catching, and not your fault.
- Sickle cells block blood flow. This causes pain and organ damage.
- Hydroxyurea is the main drug. Take shots and folic acid too.
- Good care stops most pain at home or at a Day Hospital.
- Trait is not the disease. Carriers feel fine but can pass it on.

ACTIONS · THIS WEEK

- Tell three people you know one fact about SCD this week
- Save the FFH Sickle Cell Family Glossary on your phone
- Bookmark 360SCDHUB.org
- Add SCD to your phone's medical ID

SKILLS · LIVE IT

- Explain SCD to a friend in two sentences
- Tell what happens inside a blood vessel during pain
- Tell the difference between trait and disease
- Know that a fever is an emergency in SCD

PLAN · SHARE IT

- Read all 16 squares of this Fact Sheet
- Open the deep course tile #1: Know My Condition
- Build your 30-second way to explain SCD
- Book your blood doctor visit if it is overdue



3 Force Field Fact Sheet

Primer · Foundations



360 Human Anatomy: Hematology / Vascular

PRIMER · ANATOMY

Let's walk the body where SCD lives. Bone marrow makes red cells. In SCD, these cells carry abnormal hemoglobin S. Sick cells live only about 10 to 20 days.

Normal cells live 120 days. So people with SCD have low blood counts (anemia). Stuck cells block blood flow. They harm the organs downstream. The spleen gets scarred.

Most kids' spleens stop working by age 5. That is why infection risk is high. The lungs can get acute chest syndrome. This is the number one cause of death.

SCD can also hurt the kidneys, brain, bones, and eyes. It can cause strokes you can see and strokes you can't. In men it can cause priapism (a long, painful erection).

The 360 Human Explorer lets you click each organ. You can see what SCD does there and what to watch for.

CONCEPTS · LEARN IT

- Bone marrow makes red cells → hemoglobin → vessels → organs
- Spleen damage means high infection risk for life
- Acute chest syndrome is a lung emergency
- Stroke risk: kids need a TCD ultrasound every year
- Kidney, eye, and bone damage build slowly. Screen every year.

ACTIONS · THIS WEEK

- Click into 360 Human Anatomy: Hematology
- Find your two highest-risk organs from your health story
- Mark your yearly specialist visits on a calendar
- Add 'TCD if <16' or 'echo + eye exam' to your reminders

SKILLS · LIVE IT

- Open the 360 Human Anatomy tool and click blood
- Name three organs that SCD often affects
- Tell why kids with SCD need penicillin
- Describe what acute chest syndrome feels like

PLAN · SHARE IT

- Visit 360-Human-Explorer · Hematology system
- Mark your own organs of concern
- Bring your marked map to your next blood doctor visit



3 Force Field Fact Sheet

Primer · Foundations



Who Gets Sickle Cell?

PRIMER

SCD runs in families. Both parents must pass on a sickle gene. Then their child can have the disease. If only one parent passes it on, the child has sickle cell trait.

People with trait usually feel fine. But they can pass the gene to their own kids. SCD is most common in some groups. These are people whose families came from sub-Saharan Africa, the Caribbean, and parts of South and Central America.

It is also common in people from the Mediterranean (Italy, Greece, Turkey), the Middle East, and parts of India. About 100,000 Americans have SCD. About 1 in 13 Black newborns has the trait.

In the U.S., newborn testing finds almost every case.

CONCEPTS · LEARN IT

- SCD is passed down. Both parents pass on a gene.
- Trait means one gene. Disease means two genes.
- It is most common in people with African roots, but not only them.
- Genetic counseling helps before pregnancy.
- Newborn testing finds it early. Care can start on day one.

ACTIONS · THIS WEEK

- Ask your parents and siblings if they got tested for trait
- If you may have a baby, ask about testing your partner for trait
- Put your kids' newborn test results in your folder

SKILLS · LIVE IT

- Explain trait and disease in plain words
- Read a basic punnett square
- Find your state's newborn test result

PLAN · SHARE IT

- Talk with your family about trait this month
- Get a genetic counseling referral if you plan a family
- Add trait status to your Health Passport



3 Force Field Fact Sheet

Primer · Foundations



The Numbers PRIMER

About 100,000 Americans have SCD. The U.S. spends about \$2.4 billion a year on SCD care. More than 70% of that goes to hospital stays. Many of those stays can be prevented with timely care outside the hospital.

People are living much longer now. In the 1970s, most lived only to their mid-teens. Today, many live to about their mid-50s. That number keeps rising.

It rises as more people get hydroxyurea, transfusions, and newer drugs. Hydroxyurea cuts pain flares by about half. But fewer than 1 in 4 people who could take it are on the best dose.

Day Hospitals cut hospital stays by more than 50% versus ER visits. A bone marrow transplant or gene therapy can cure some people.

CONCEPTS · LEARN IT

- ~100,000 Americans · ~\$2.4B/yr U.S. spend
- More than 70% of the cost is hospital stays that can be prevented
- Hydroxyurea cuts pain flares ~50%
- Day Hospital beats the ER on cost, results, and respect
- Cures for some: matched-sibling bone marrow transplant, gene therapy

ACTIONS · THIS WEEK

- Track your ER visits, hospital stays, and Day Hospital visits this year
- Work out how often you take your hydroxyurea, as a percent
- Ask your blood doctor about gene therapy or transplant

SKILLS · LIVE IT

- Say one number that keeps you going
- Work out your own ER vs. Day Hospital cost gap
- Read a basic SCD outcomes paper

PLAN · SHARE IT

- Add an outcomes log to your Health Passport
- Set a goal, like 0 ER visits and >90% of doses taken
- Opt in to PHIT to add to the program's national results



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Know My Condition

LEARN IT · TIER 1 AWARE

"SCD" is a big umbrella. Your exact type changes how the disease acts. It also changes which treatments fit you. There are four common types. HbSS is the most severe.

It is the classic 'sickle cell anemia.' HbS β^0 -thalassemia acts like HbSS. HbSC is often milder. But it still causes pain flares and problems. HbS β^+ -thalassemia is often the mildest.

Know your type. Know your baseline hemoglobin. Know your reticulocyte count (a count of new red cells). Know what sets off your pain. This is the base for everything else.

It shapes which meds and screenings fit you.

CONCEPTS · LEARN IT

- Your type shapes how bad it is, and your treatment and screening
- HbSS & HbS β^0 act alike. They are the most severe.
- HbSC & HbS β^+ are often milder. But they still need checkups.
- Baseline labs help you spot trouble early
- Knowing your story keeps you from being treated as 'generic'

ACTIONS · THIS WEEK

- Get your last hemoglobin electrophoresis report (the test that shows your type)
- Write your type, baseline H&H, and triggers on your Passport
- Teach a family member your type and baseline
- Check that your type is right in MyChart

SKILLS · LIVE IT

- Say your exact type out loud
- Read your baseline CBC and reticulocyte count
- Describe what usually sets off your pain, and when
- Know the early warning signs that are yours

PLAN · SHARE IT

- This week: find your type lab report
- Bring it to your next blood doctor visit to confirm
- Update your Health Passport with baseline labs



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Master Meds & Devices

LEARN IT · TIER 1 AWARE

Hydroxyurea is the main drug. It is a daily pill. It raises fetal hemoglobin (a gentler type of hemoglobin). It cuts sickling and pain flares by about half.

It also adds years of life. Take folic acid every day. It replaces what your body uses to make new red cells. Kids under 5 take penicillin every day. It stops a deadly pneumococcal infection.

You also need a written pain plan made just for you. Newer drugs help in certain cases. These are voxelotor, crizanlizumab, and L-glutamine. Vaccines are a must.

Get them for pneumococcal, meningococcal, flu, RSV, and COVID. Do you have a port, or get regular transfusions or exchanges? Then port care and iron checks become daily skills.

CONCEPTS · LEARN IT

- Hydroxyurea is the main drug. Take it daily, even when you feel fine.
- Folic acid daily. Penicillin for kids. Vaccines on time.
- Written pain plan: home step → clinic step → ER step
- Newer drugs target certain problems
- Port care, transfusion logs, and iron checks if they apply to you

ACTIONS · THIS WEEK

- Set a daily hydroxyurea reminder
- Bring your full med list to your next visit
- Ask: 'Am I on the best dose for me?'
- Add iron / ferritin to your yearly labs if you get transfusions
- Update your Passport with all your meds and devices

SKILLS · LIVE IT

- Go over your med list at every visit
- Explain what hydroxyurea does and how you take it
- Use a pillbox or app reminder
- Show how to flush a port (if you have one)
- Say your home pain plan from memory

PLAN · SHARE IT

- This week: set up or update your pillbox routine
- This month: talk about your best dose with your blood doctor
- This quarter: get any vaccines you missed



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Spot Red Flags Early

LEARN IT · TIER 1 AWARE

Some SCD symptoms are emergencies even if they look mild. Treat each one as a reason to call BEFORE you drive anywhere. A fever of 101°F (38.5°C) or higher? Call within one hour.

People with SCD have damaged spleens. They can die from infection in hours. Chest pain or trouble breathing could be acute chest syndrome. This is the top cause of death in adults.

Stroke signs need 911. These are face droop, arm weakness, slurred speech, or a sudden bad headache. Priapism (an erection) lasting more than 2 hours means go in.

A big, tender belly with pale skin can be splenic sequestration. This is very serious, mostly in kids. Is bad pain not easing with your home plan after the set time? Call your team first, not the ER.

CONCEPTS · LEARN IT

- Fever 101°F or higher is an emergency. Call within 1 hour.
- Chest pain or trouble breathing could be acute chest syndrome
- FAST stroke signs? Call 911.
- Priapism over 2 hours means go to the ER
- Pain not easing at home? Call your team first, not the ER.
- Splenic sequestration in kids: big belly, pale skin, scared child

ACTIONS · THIS WEEK

- Save the When-to-Call numbers in your phone today
- Print a Red Flag card for the fridge
- Practice out loud: 'When do I call, drive, or dial 911?'
- Check that your blood clinic has 24/7 on-call help

SKILLS · LIVE IT

- Take a temperature the right way
- Know the FAST stroke signs
- Say the When-to-Call numbers
- Use a home pulse oximeter and know when to act on the reading
- Run your home pain plan, time it, and know when to go in

PLAN · SHARE IT

- This week: put a red flag card on the fridge
- This month: practice one fever plan with family
- Each quarter: review your pain plan with your blood clinic



3 Force Field Fact Sheet

Tier 1 · Learn It · Aware



Triggers & Mind–Body

LEARN IT · TIER 1 AWARE

Sickling is more likely when red cells are stressed. Common triggers are low oxygen, too little water, and cold. Others are infection, being worn out, alcohol, and smoke.

Big emotional stress can do it too. You can't avoid every trigger. But you can stack the odds in your favor. Drink water. Wear warm layers. Keep a steady sleep routine.

Get your vaccines. Use mind-body skills. These include slow breathing, muscle relaxing, music, imagery, and biofeedback. Studies show they cut how often and how bad pain flares get.

On long flights or at high places, oxygen can drop. Tell the flight crew if you need extra oxygen.

CONCEPTS · LEARN IT

- Triggers: cold, too little water, low O₂, stress, infection, smoke, alcohol
- Mind-body skills clearly lower pain
- Water is daily medicine
- A steady sleep routine matters as much as meds
- High places and planes can drop your O₂. Plan ahead.

ACTIONS · THIS WEEK

- Carry a water bottle every day
- Set a sleep schedule: same time, same place
- Layer up before you go out in the cold
- Tell your airline, school, or job about cold or altitude needs
- Try one mind-body app or class this month

SKILLS · LIVE IT

- Drink to a daily water goal (often 64–96 oz, set for you)
- Do a 4-7-8 breathing cycle
- Lead a 5-minute imagery script for a child
- Warm up before exercise or cold outdoor work
- Stay away from smoke and tobacco completely

PLAN · SHARE IT

- Daily: drink water, breathe, sleep
- Weekly: practice one mind-body skill
- Each season: plan ahead for cold or travel



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Make Every Visit Count

LIVE IT · TIER 2 ACTIVE

A great visit is not about cramming. It is about a few key steps. Bring three questions. Do one teach-back. Make one shared choice. Set one clear next step.

Bring your Health Passport. Write down your top three questions. Use the SHARE Approach: Seek, Help, Assess, Reach, Evaluate. Ask: 'If you were me, what would you do?' Before you leave, say your next three steps out loud.

Make sure your clinician agrees.

CONCEPTS · LEARN IT

- 3 questions · 1 teach-back · 1 shared choice
- Your Health Passport is a short summary you carry
- The SHARE Approach beats just asking
- Map your next steps before you leave the room
- Your list comes first, then the clinician's

ACTIONS · THIS WEEK

- Before the visit: write 3 questions and update your Passport
- During the visit: do one teach-back
- After the visit: list 3 next steps and share with your caregiver
- Follow up through the portal within 24 hours

SKILLS · LIVE IT

- Write three questions in order of what matters most
- Do a teach-back ('Let me say this back to you')
- Ask 'What would you do if you were me?'
- Sum up your next steps before you leave
- Send a follow-up portal message within 24 hours

PLAN · SHARE IT

- Set up a before-visit routine (15 min, the day before)
- Practice teach-back with family before a real visit
- Plan a quick recap with your caregiver after each visit



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Care Team Members

LIVE IT · TIER 2 ACTIVE

SCD takes a team. You need a blood doctor (hematologist) and a primary care doctor. You need a pain specialist. You need mental health support. Depression and pain-linked worry are common.

You need a social worker. You need eye care every year and a heart echo every year. You may need a kidney doctor if your kidneys are affected. You need an OB if you are pregnant.

Teens need a transition counselor to move to adult care. You may need a geneticist for family planning. You may need a school nurse or HR contact. Build the list.

Save the numbers. Know who does what. Keep a Care Team card on your fridge and phone. It keeps things from turning into chaos.

CONCEPTS · LEARN IT

- SCD care is a team sport
- Yearly checks: eyes, heart echo, kidneys, TCD (for kids)
- Mental health is part of SCD care, not a luxury
- Moving from kid care to adult care is high-risk
- Family planning and OB need clinicians who know SCD

ACTIONS · THIS WEEK

- Build the Care Team card
- Book next year's yearly checks this month
- Find a mental health pro who knows SCD
- If you are a teen: name your transition coordinator

SKILLS · LIVE IT

- List each team member with a phone and email
- Use a 'who handles what' plan
- Book yearly checks 12 months ahead
- Hold a transition meeting at age 16-18

PLAN · SHARE IT

- This month: finish your Care Team card
- This quarter: book the yearly check you're missing
- This year: finish your transition plan if you're under 25



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Telemedicine & Tech

LIVE IT · TIER 2 ACTIVE · TECH

Telemedicine and health tech now do real work in SCD. Video visits handle most routine blood-clinic follow-ups. They work for med reviews and dose changes too.

Patient portals like MyChart let you message your team and see your labs. A home pulse oximeter (a clip that reads your oxygen, under \$30) and a thermometer help a lot.

They turn 'is this an emergency?' guessing into real data. Wearables track sleep, heart rate, and oxygen drops. Tele-pain coaching, digital pain diaries, and mind-body apps can make pain less severe.

AI symptom triage is new. It can help. But it never replaces calling your team.

CONCEPTS · LEARN IT

- Telemedicine is real medicine, not 'less'
- The patient portal is your second voice
- A home pulse-ox and thermometer are must-haves
- Wearables flag drops in O₂ and sleep
- Pain diary apps make your patterns clear
- AI triage helps, but it does not replace your team

ACTIONS · THIS WEEK

- Sign up for your portal today
- Buy a home pulse oximeter and a thermometer
- Book one routine visit as a video visit
- Try a digital pain diary for 30 days
- Set wearable alerts that fit your goals

SKILLS · LIVE IT

- Run a video visit well (camera, light, and your med list)
- Send a clear portal message (subject, key facts, your ask)
- Read a home pulse-ox and act on it
- Log a pain flare in a pain diary
- Link a wearable to your phone and check the trends

PLAN · SHARE IT

- This week: portal, pulse-ox, thermometer
- This month: try a video visit
- This quarter: review a 30-day pain diary with your blood doctor



3 Force Field Fact Sheet

Tier 2 · Live It · Active



Insurance, Referrals & Cost

LIVE IT · TIER 2 ACTIVE

Cost should never send a person with SCD to the ER instead of a Day Hospital. Hydroxyurea is generic and cheap. Day Hospitals cost less than ER visits.

They also lead to fewer hospital stays. Help with co-pays is real. Groups like SCDA, NORD, and the HealthWell Foundation help. Drug company programs help too.

They cover much of the gap. You can appeal a prior authorization (when insurance says no first). FMLA and ADA are laws. They cover time off from school and work for SCD.

Medicaid covers many SCD services in most states. Care navigators help with all of this. They are often free at big medical centers.

CONCEPTS · LEARN IT

- Day Hospital beats the ER on every measure
- Hydroxyurea is generic and cheap
- Co-pay help: SCDA, NORD, HealthWell, drug company programs
- You can appeal a prior auth that gets refused
- FMLA and ADA are your rights at work and school
- Care navigators are free or low-cost

ACTIONS · THIS WEEK

- Print one EOB and learn what each line means
- Map your co-pays for hydroxyurea, voxelotor, and more
- Save 3 co-pay help links in your phone
- Talk to HR about FMLA forms before you need them

SKILLS · LIVE IT

- Read an EOB and find where to send an appeal
- File a prior auth appeal
- Apply for SCDA, NORD, or HealthWell co-pay help
- Get FMLA forms from HR
- Find your local care navigator

PLAN · SHARE IT

- This week: gather your last 3 EOBs
- This month: apply for at least one co-pay program
- Each year: recheck your FMLA / ADA forms at work or school



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Stigma, Equity & Access

SHARE IT · TIER 3 CERTIFIED

Many studies show SCD pain gets under-treated. This happens even next to other conditions just as severe. Often, clinicians are not trained well in SCD.

They wrongly read normal pain-coping as drug-seeking. SCD has also gotten less funding than its heavy toll deserves. None of this is your fault. And you do not have to just live with it.

Know your rights. Write down your visits. Bring someone to speak up for you. Use the SHARE Approach. Speak up safely. Use calm words, a calm tone, and written follow-ups.

When it feels safe, share your story. When it does not, leave and find a better team.

CONCEPTS · LEARN IT

- Pain bias is real. The research backs you up.
- Write down everything: date, time, what you asked, what was said or done
- Bring someone to speak up (family, friend, or navigator)
- Stay calm in the moment. Speak up after.
- Switch teams when you need to. You're allowed.

ACTIONS · THIS WEEK

- Save written notes after each visit
- Build your story toolkit (3 stories, 3 phrases)
- Find a local advocate who knows SCD
- Practice the 'broken record' way of repeating your point

SKILLS · LIVE IT

- Write down a visit (date, names, asks, outcomes)
- Use calm words ('I want to work with you on this. Here's what has helped me before.')
- Ask calmly for a different clinician
- File a patient experience complaint

PLAN · SHARE IT

- This month: finish one stigma-and-equity training (SCDAA / IHI)
- This quarter: write your story and decide who to share it with
- Long-term: become an Ambassador (Tier 3)



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Teach, Mentor, Ambassador

SHARE IT · TIER 3 CERTIFIED

You grow strongest when you teach others what you've learned. Mentor a newly diagnosed family at your blood clinic. Speak at your school, your place of worship, or your job.

Lead a peer group online. Share parts of your Health Passport. Then the next person won't start from zero. Volunteer with SCDA or 360SCDHUB. Join panels.

Train residents and ER staff. You're not 'just a patient.' You're the world's top expert on living with your version of SCD.

CONCEPTS · LEARN IT

- Mentoring helps your own health too
- Teach what you really do, not just theory
- One clear story beats ten slides
- Setting limits is part of mentoring
- Bring data: your Passport and your numbers

ACTIONS · THIS WEEK

- Sign up to mentor one newly diagnosed family
- Speak once at school, work, church, or in your community
- Send your story to SCDA or 360SCDHUB
- Co-present grand rounds with your blood care team

SKILLS · LIVE IT

- Tell your story in 3 minutes
- Run a 30-minute peer support session
- Write a one-pager: 'what I wish I'd known at __'
- Co-teach a clinical workshop with your blood doctor
- Set healthy limits when you mentor

PLAN · SHARE IT

- This month: find one place to mentor
- This quarter: give one talk
- This year: finish the Tier 3 Ambassador steps



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Share Insights with Clinicians

SHARE IT · TIER 3 CERTIFIED

This square is the bridge from your own care to system change. Write a short note to your care team after a visit. It works after a great visit or a rough one.

Say what worked, what didn't, and what you learned together. Volunteer for resident teaching rounds. Most academic programs welcome patient teachers. Share real moments.

Like 'the time the ER nurse treated me with respect.' Or 'the time the doctor really listened.' Or 'what I wish I'd known at 16.' Your insight changes care for the patients who come after you.

CONCEPTS · LEARN IT

- Letters to clinicians are short, clear, and name real people
- Real stories beat general feedback
- Most teaching programs welcome patient teachers
- Even nameless insights still help
- Feedback closes the loop on shared choices

ACTIONS · THIS WEEK

- Write one feedback letter this quarter
- Volunteer for one teaching round this year
- Send one insight to the FFH Network for the staff training library

SKILLS · LIVE IT

- Write a 'what worked / what didn't / what we learned' letter in under 200 words
- Lead a 5-minute slot in resident teaching rounds
- Send a portal thank-you after a great visit
- Turn a hard moment into a teaching case (with consent)

PLAN · SHARE IT

- This month: write one feedback letter
- This quarter: present once
- This year: add to the FFH Staff Training Library



3 Force Field Fact Sheet

Tier 3 · Share It · Certified



Join the ROI Study (PHIT)

SHARE IT · TIER 3 CERTIFIED · STUDY

PHIT stands for Population Health Impact Tracking. It is the FFH research engine. It asks one big question. Does the Prepared Patient program really cut ER visits, hospital stays, and total care cost? You can opt in to share your outcomes.

The data is grouped and de-identified (your name is removed). It includes visits, hospital stays, badge progress, and how you rate your quality of life.

This lets researchers, payers, and lawmakers test the program. No private health info (PHI) is shared. You can withdraw anytime. You'll get plain-language updates on how the group is doing.

CONCEPTS · LEARN IT

- PHIT uses grouped, de-identified outcomes only
- Proven programs become paid-for and can grow
- Your data plus 1,000 others makes a study worth publishing
- Opt out anytime, with full openness
- The FFH ROI Engine pairs PHIT data with cost data

ACTIONS · THIS WEEK

- Opt in through the green box on this page
- Read your first quarterly update
- Tell one peer about PHIT
- If a researcher contacts you, check with FFH first

SKILLS · LIVE IT

- Read a one-page consent form
- Know what is and isn't private health info (PHI)
- Set up a regular check of your own dashboard
- Withdraw or pause anytime

PLAN · SHARE IT

- Today: opt in if it feels right
- Each quarter: read your update
- Each year: decide if you want to keep going

Additional Notes

☐ I've read the full Sickle Cell Disease Fact Sheet · Step 3


4 Prepared Patient Course

The complete course — three levels, applied to your life

The course takes you through the Fact Sheet in three levels — from newly-diagnosed to prepared — then shows how every part applies to you and the people around you.

Level 1 · Aware

Know the basics — what Sickle Cell Disease is, your numbers, your meds.

Level 2 · Active

Manage & do — self-monitor, act on red flags, work your plan.

Level 3 · Certified

Advocate & share — teach it, bring your team in, help others.

The Numbers

About 100,000 Americans have SCD. The U.S. spends about \$2.4 billion a year on SCD care. More than 70% of that goes to hospital stays. Many of those stays can be prevented with timely care outside the hospital.

People are living much longer now. In the 1970s, most lived only to their mid-teens. Today, many live to about their mid-50s. That number keeps rising.

It rises as more people get hydroxyurea, transfusions, and newer drugs. Hydroxyurea cuts pain flares by about half. But fewer than 1 in 4 people who could take it are on the best dose.

Day Hospitals cut hospital stays by more than 50% versus ER visits. A bone marrow transplant or gene therapy can cure some people.

- ~100,000 Americans · ~\$2.4B/yr U.S. spend
- More than 70% of the cost is hospital stays that can be prevented
- Hydroxyurea cuts pain flares ~50%
- Day Hospital beats the ER on cost, results, and respect
- Cures for some: matched-sibling bone marrow transplant, gene therapy

THE FULL COURSE — HOW EACH PART APPLIES TO YOUR LIFE

Every part of the Sickle Cell Disease Force Field lands differently depending on who you are. Here is the complete course — what each concept means for **you**, your **family**, the **workplace**, and **students** learning it.



4 Prepared Patient Course

The complete course — three levels, applied to your life

What Is Sickle Cell Disease?

FOR YOU · THE PATIENT

This is your map. Read it once all the way through. Then come back square by square. You get stronger each step.

EMPLOYERS & WORKPLACE

SCD is a real, lifelong disease. People with SCD work, study, raise kids, and lead. Small changes help a lot. These include water breaks, warm spaces, and flexible hours around pain flares.

FAMILY & CAREGIVERS

You don't have to learn all the science. Learn enough to spot a fever, low fluids, or chest pain. And back up the patient at visits.

STUDENTS & LEARNERS

Sickle cell shows how genes, blood vessels, infection, and pain care all meet. You will see SCD in the lab, ER, blood clinic, and OB. Learn it well. Patients can tell who knows.

360 Human Anatomy: Hematology / Vascular

FOR YOU · THE PATIENT

Knowing where the disease lives in your body makes the rest make sense. It explains your meds, your screenings, why fever matters, and why water matters.

EMPLOYERS & WORKPLACE

This shows why a person with SCD may need warm break rooms, water, and time off after pain. The damage is real and physical.

FAMILY & CAREGIVERS

Use the 360 Human Anatomy together. It turns scary words into clear pictures.

STUDENTS & LEARNERS

This is the best free anatomy tool for SCD. Bookmark it for tests and bedside.

Who Gets Sickle Cell?

FOR YOU · THE PATIENT

You did not cause this. Knowing your family history helps you, your siblings, and your future kids.

EMPLOYERS & WORKPLACE

SCD is not catching. Full stop. You cannot get it from a coworker.

FAMILY & CAREGIVERS

Ask: 'Have we all been tested for trait?' This is one of the most loving things a family can do.

STUDENTS & LEARNERS

Genetic counseling for SCD helps a lot and costs little. Know how to refer.



4 Prepared Patient Course

The complete course — three levels, applied to your life

The Numbers

FOR YOU · THE PATIENT

You are not a statistic. But the numbers fight for you. Use them with insurers, employers, and your care team.

EMPLOYERS & WORKPLACE

Support for SCD saves money and keeps workers at work. So does covering Day Hospital care.

FAMILY & CAREGIVERS

These numbers show why early action matters. Pushing for hydroxyurea is one of the best things you can do.

STUDENTS & LEARNERS

Learn three numbers: ~100k, ~\$2.4B, and hydroxyurea cuts flares ~50%. You'll use them on the wards and on tests.

Know My Condition

FOR YOU · THE PATIENT

Two minutes learning your type can stop a wrong med and a long ER wait. It may be the most useful thing on this whole sheet.

EMPLOYERS & WORKPLACE

You don't need this. But if a teammate shares it, believe them. Respect how serious it is.

FAMILY & CAREGIVERS

Learn the type by heart. It belongs on every emergency contact card.

STUDENTS & LEARNERS

Hemoglobin electrophoresis is a key test. Know how to read it and how to explain it to a patient.

Master Meds & Devices

FOR YOU · THE PATIENT

Taking your meds is the #1 thing you control. Missing hydroxyurea is the top reason pain flares stay frequent.

EMPLOYERS & WORKPLACE

Daily meds are a normal part of the workday. A quiet spot to take meds and a fridge for some shots costs little and builds trust.

FAMILY & CAREGIVERS

Help build the routine. Don't nag. Pillboxes, calendars, and shared phone reminders work better than reminders from you.

STUDENTS & LEARNERS

Know these cold, with their uses: hydroxyurea, folic acid, penicillin (kids), vaccines, voxelotor, crizanlizumab, L-glutamine.

Spot Red Flags Early

FOR YOU · THE PATIENT

This square saves lives. Treat fever and chest pain like fire alarms, not maybes.

EMPLOYERS & WORKPLACE

If a teammate says 'fever' or 'chest pain,' take it seriously. Help them call their team or 911. Do not wait and see.

FAMILY & CAREGIVERS

Caregivers often spot red flags before patients do. You may be the hero. Be ready.

STUDENTS & LEARNERS

Know these five red flags cold: fever, acute chest, stroke, priapism, and splenic sequestration. Don't miss them.



4 Prepared Patient Course

The complete course — three levels, applied to your life

Triggers & Mind–Body

FOR YOU · THE PATIENT

You can cut your pain flares with small daily habits. They feel boring. They work.

EMPLOYERS & WORKPLACE

A warm break room, water, and steady hours can mean fewer ER visits and fewer missed days.

FAMILY & CAREGIVERS

Help set up the habits: water bottles, warm layers in the car, and a calm evening routine.

STUDENTS & LEARNERS

Don't just tell a patient to 'hydrate.' Teach them how: a daily goal, signs of low fluids, and what works for kids.

Make Every Visit Count

FOR YOU · THE PATIENT

Great visits don't just happen. You build them. Five minutes of prep makes 50 minutes of better care.

EMPLOYERS & WORKPLACE

A 30-minute window for medical visits, with no judgment, saves money later and keeps workers engaged.

FAMILY & CAREGIVERS

Be the second set of ears. Help write down next steps.

STUDENTS & LEARNERS

Use the SHARE Approach in every visit. It feels awkward for two weeks. Then it feels like medicine.

Care Team Members

FOR YOU · THE PATIENT

You don't need to know everything. You need to know who knows what, and how to reach them.

EMPLOYERS & WORKPLACE

Work with the patient's HR or school contact. One named person on each side stops chaos.

FAMILY & CAREGIVERS

Help keep the Care Team card up to date. It is hard to do alone during a crisis.

STUDENTS & LEARNERS

Become the SCD-savvy clinician this community needs. There are not enough of you.

Telemedicine & Tech

FOR YOU · THE PATIENT

Tech gives you more power. Video visits save hours of travel. A pulse-ox saves hours of worry.

EMPLOYERS & WORKPLACE

A 30-minute video visit during work is far easier than a half-day in clinic. Allow it.

FAMILY & CAREGIVERS

Set up the tools together. Make sure parents and caregivers also have portal access.

STUDENTS & LEARNERS

Tele-hematology is the future. Learn it now. Patients will come to you fluent in MyChart and pain diaries.



4 Prepared Patient Course

The complete course — three levels, applied to your life

Insurance, Referrals & Cost

FOR YOU · THE PATIENT

A few hours of paperwork can save you thousands and skip most ER bills. It feels worth it after your first win.

EMPLOYERS & WORKPLACE

FMLA, ADA, and early HR support save money, keep talent, and cut risk. Get ahead of it.

FAMILY & CAREGIVERS

Take the lead on paperwork during a crisis. The patient should not be on hold during a pain crisis.

STUDENTS & LEARNERS

Most clinicians don't teach this. If you learn it, you'll be the most useful person on the team.

Stigma, Equity & Access

FOR YOU · THE PATIENT

You are not making this up. The system is uneven. Knowing that lets you protect yourself, write things down, and pick teams who get it.

EMPLOYERS & WORKPLACE

Believe what your team member tells you. Bias in the medical system is well proven. They are not imagining it.

FAMILY & CAREGIVERS

Be the calm voice. Be the second witness. Be the one who writes it down. Your role is real medicine.

STUDENTS & LEARNERS

Read 'Why Sickle Cell Patients Wait Longer' and papers like it. Then change your own behavior. You are the next generation.

Teach, Mentor, Ambassador

FOR YOU · THE PATIENT

Teaching locks in what you know. It also gives meaning to what you've been through.

EMPLOYERS & WORKPLACE

A teammate who mentors becomes a champion inside your team. Support them: pay for travel and give them time.

FAMILY & CAREGIVERS

Caregiver-to-caregiver mentoring is just as strong as patient-to-patient.

STUDENTS & LEARNERS

Learning with patient-experts is how you become an SCD-savvy clinician. Show up. Listen first.

Share Insights with Clinicians

FOR YOU · THE PATIENT

Your feedback may be what changes how 100 future patients are treated.

EMPLOYERS & WORKPLACE

Ask workers to share what works for them. Pass it on (with consent) to other teammates.

FAMILY & CAREGIVERS

Caregiver feedback matters too. Especially the in-between moments clinicians never see.

STUDENTS & LEARNERS

The best teaching you'll ever get is from a patient. Show up to those rounds early and stay late.



4 Prepared Patient Course

The complete course — three levels, applied to your life



Join the ROI Study (PHIT)



FOR YOU · THE PATIENT

Joining is a quiet but real act of advocacy. It helps the program get paid for, grow, and reach people who can't afford it.



EMPLOYERS & WORKPLACE

Sponsoring a group of workers in PHIT shows your investment is working. It gives you data to defend the spend.



FAMILY & CAREGIVERS

Caregivers can opt in too. Caregiver load and outcomes are tracked as well.



STUDENTS & LEARNERS

This is participatory research done right. Study how PHIT was built. Then copy it.

QUIZ YOURSELF — CAN YOU ANSWER THESE WITHOUT NOTES?

- ☐ What is Sickle Cell Disease, in one plain sentence?
- ☐ What are my target numbers, and my personal baseline?
- ☐ What are my red flags — the signs that mean “call now”?
- ☐ What do I do first if those red flags happen?
- ☐ What is each of my medicines for?

The one thing about Sickle Cell Disease I most want to remember



Additional Notes

☐ I've completed Step 4 · Prepared Patient Course for Sickle Cell Disease



5 Materials & Tools

Your home kit — the tools that keep you prepared

Being prepared between visits takes a few simple tools. Set these up for Sickle Cell Disease, and check them off as you go.

YOUR KIT

- ☐ **Health Passport** — meds, numbers, allergies & contacts on one page.
- ☐ **Your meters / devices** — whatever you use to track Sickle Cell Disease at home.
- ☐ **Your action plan** — green / yellow / red: what to do at each level.
- ☐ **Reminders** — a pillbox or phone alarm for medicines and refills.
- ☐ **A tracker** — one number or habit to watch over time.

THIS WEEK'S ACTIONS FOR SICKLE CELL DISEASE

- ☐ Tell three people you know one fact about SCD this week
- ☐ Save the FFH Sickle Cell Family Glossary on your phone
- ☐ Bookmark 360SCDHUB.org
- ☐ Add SCD to your phone's medical ID
- ☐ Click into 360 Human Anatomy: Hematology
- ☐ Find your two highest-risk organs from your health story
- ☐ Mark your yearly specialist visits on a calendar
- ☐ Add 'TCD if <16' or 'echo + eye exam' to your reminders
- ☐ Ask your parents and siblings if they got tested for trait
- ☐ If you may have a baby, ask about testing your partner for trait
- ☐ Put your kids' newborn test results in your folder
- ☐ Track your ER visits, hospital stays, and Day Hospital visits this year

The one number or habit I'll keep an eye on



5 Materials & Tools

Your home kit — the tools that keep you prepared

Additional Notes

☐ I've completed Step 5 · Materials & Tools for Sickle Cell Disease





Skills Lab is where you **show** an educator (or a trusted person) the hands-on parts of managing Sickle Cell Disease, in your own words. Practise and demonstrate these:

SKILLS TO DEMONSTRATE

- ☐ Explain SCD to a friend in two sentences
- ☐ Tell what happens inside a blood vessel during pain
- ☐ Tell the difference between trait and disease
- ☐ Know that a fever is an emergency in SCD
- ☐ Open the 360 Human Anatomy tool and click blood
- ☐ Name three organs that SCD often affects
- ☐ Tell why kids with SCD need penicillin
- ☐ Describe what acute chest syndrome feels like
- ☐ Explain trait and disease in plain words
- ☐ Read a basic punnett square
- ☐ Find your state's newborn test result
- ☐ Say one number that keeps you going
- ☐ Work out your own ER vs. Day Hospital cost gap
- ☐ Read a basic SCD outcomes paper

TEACH IT BACK

The fastest way to know you've got it: explain Sickle Cell Disease in your own words — what it is, your main signs, what helps, and your red flags — with no notes.

My red flags for Sickle Cell Disease — the signs that mean “call now”



6

Skills Lab

Show you can do it — hands-on teach-back

Additional Notes

☐ I've completed Step 6 · Skills Lab for Sickle Cell Disease





THE FORCE FOR HEALTH® · PREPARED PATIENT

Prepared Patient Ambassador

This certifies that

has completed the Prepared Patient module for **Sickle Cell Disease** —
knowing their condition, their numbers, their red flags, and how to speak up
in their own care.

SKILLS-LAB EDUCATOR SIGN-OFF

DATE

Workbook completion certificate. The clinical Prepared Patient Ambassador credential is confirmed by your
Skills-Lab educator or the certification exam.



SCAN TO VERIFY &
COMPLETE
CERTIFICATION

8 Disease Advocate

Optional — beyond yourself: help those who come after you

This optional step is a gift you give the next person. Turn what you learned about Sickle Cell Disease outward.

WAYS TO ADVOCATE & SHARE

- ☐ Read all 16 squares of this Fact Sheet
- ☐ Open the deep course tile #1: Know My Condition
- ☐ Build your 30-second way to explain SCD
- ☐ Book your blood doctor visit if it is overdue
- ☐ Visit 360-Human-Explorer · Hematology system
- ☐ Mark your own organs of concern
- ☐ Bring your marked map to your next blood doctor visit
- ☐ Talk with your family about trait this month
- ☐ Get a genetic counseling referral if you plan a family
- ☐ Add trait status to your Health Passport
- ☐ Share your story and what helped you most.
- ☐ Complete a row of Advocate Bingo.
- ☐ Support someone newly diagnosed with Sickle Cell Disease.

My feedback on this program (Coach Lucy & Dr. Rob read these)



8 Disease Advocate

Optional — beyond yourself: help those who come after you

Additional Notes

☐ I've completed Step 8 · Disease Advocate for Sickle Cell Disease

