

So your newborn baby has sickle cell disease....What's next?



Wanda Whitten – Shurney MD

CEO / Medical Director
Sickle Cell Disease Association of America
Michigan Chapter



OVERVIEW

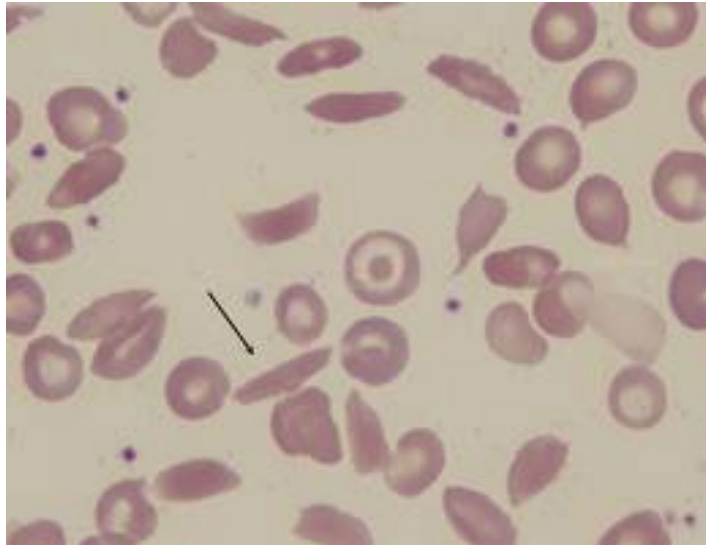
- The First Encounter
- Anticipatory Guidance
- Transitioning Care

- History
- SCDAAMI

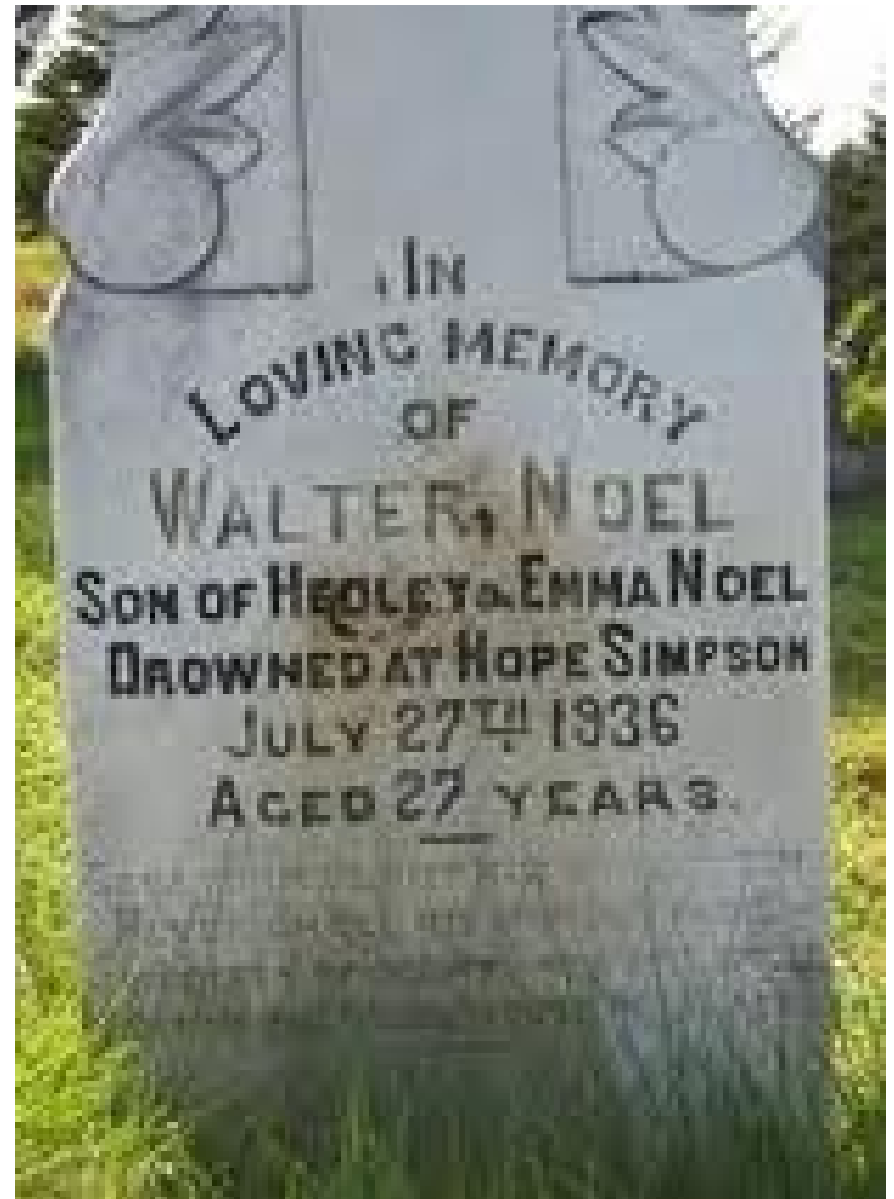


James Herrick – 1910

First patient diagnosed
With SCD in United States



Walter Clemons Noel



"peculiar elongated and sickle shaped"
red blood cells in
"an intelligent negro of 20."



Chwechweechwe
(Ga)

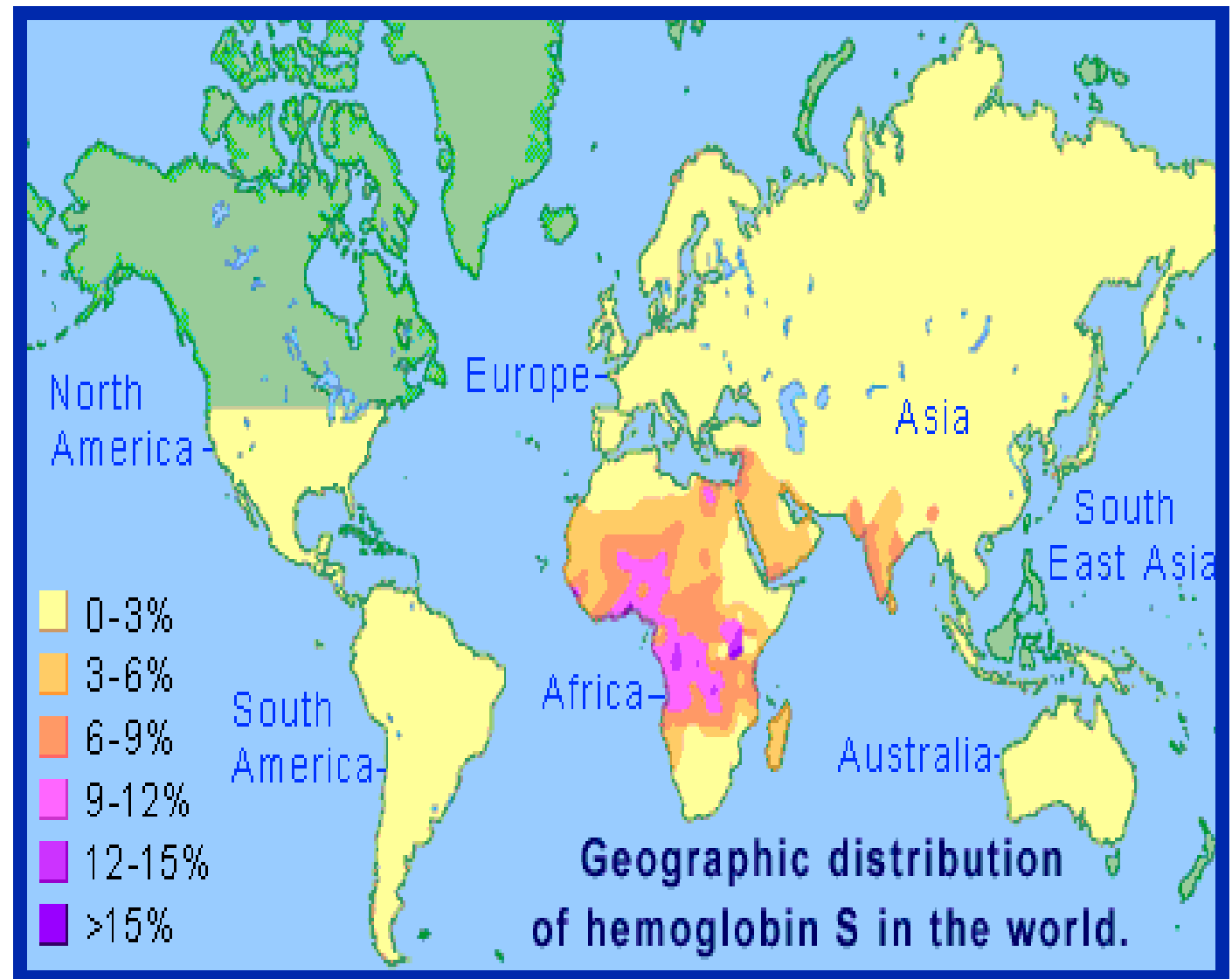
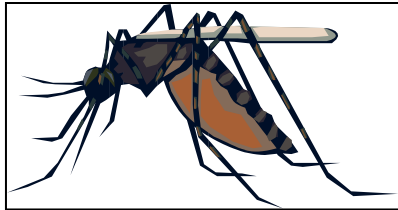


Ahotutuo (Twi)

Nwiiwii (Faute)

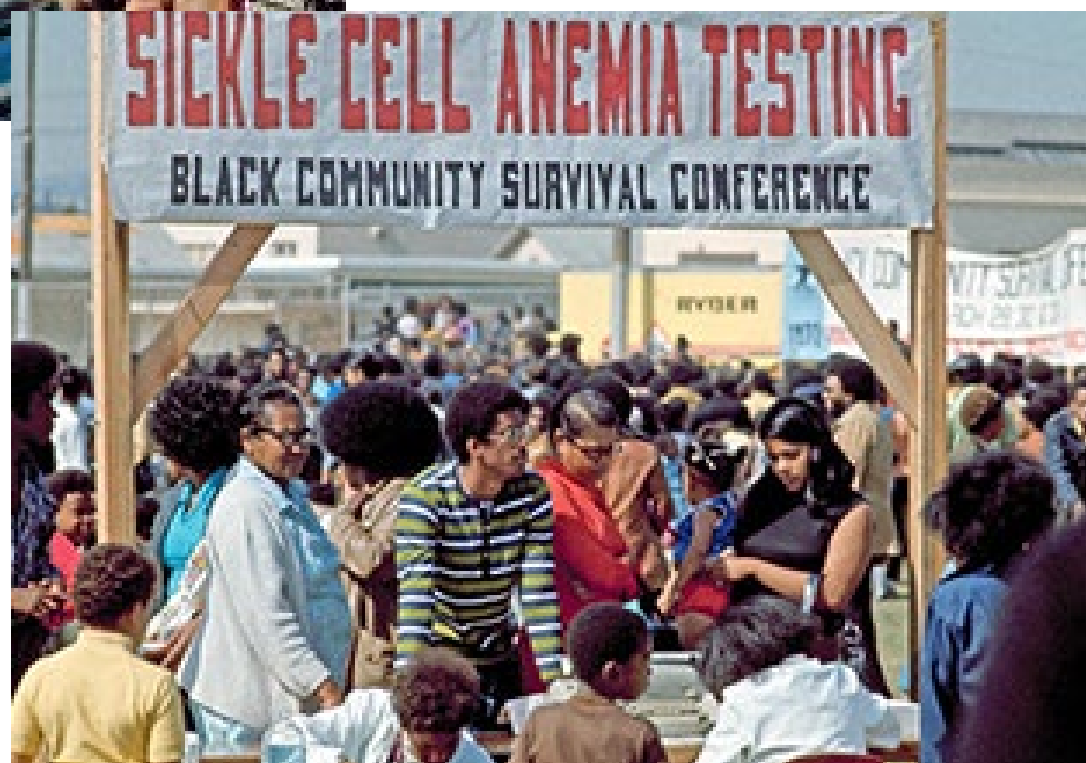
Nuidudui (Ewe)

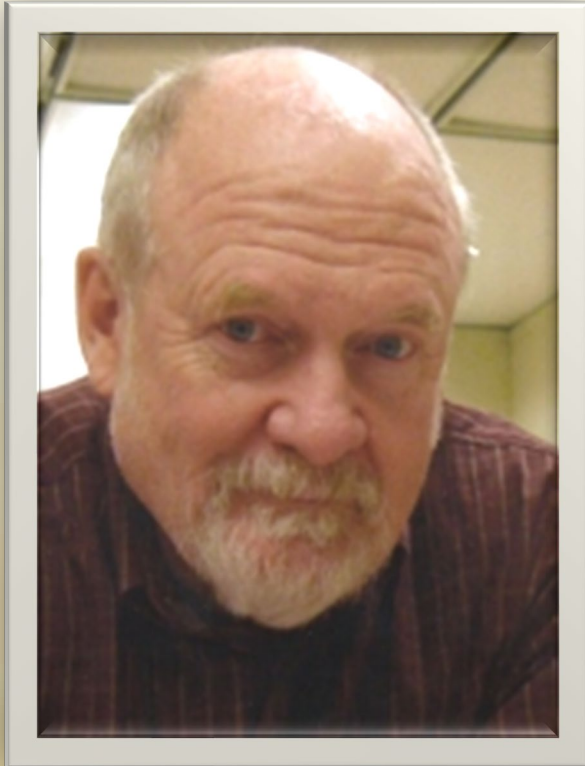




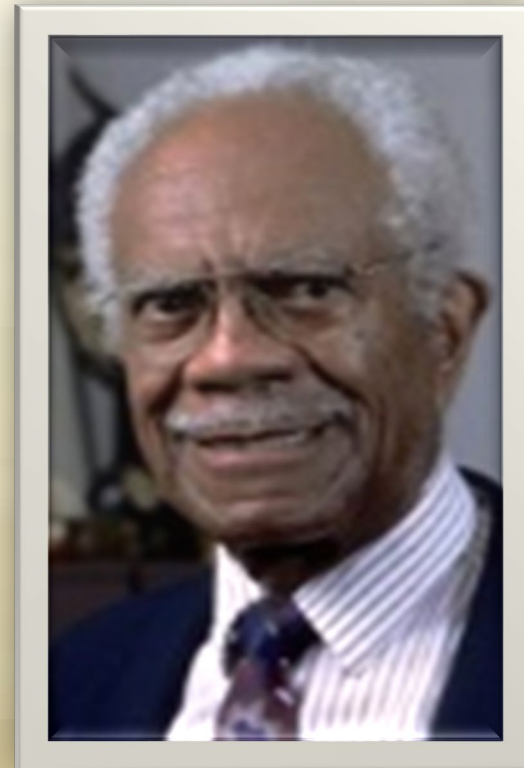
MALARIA







Dr. William Young

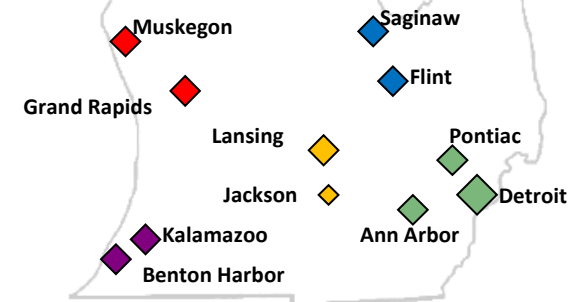


Dr. Charles Whitten



SCDAA MI Patient Advocates

Ann Arbor
Benton Harbor
Detroit (CHM/PVT)
Flint
Grand Rapids
Jackson
Kalamazoo
Lansing
Muskegon
Pontiac
Saginaw



OUR MISSION

- TO MAXIMIZE THE QUALITY LIFE OF INDIVIDUALS LIVING WITH SCD
- TO ENABLE INDIVIDUALS WITH SICKLE CELL TRAIT TO MAKE INFORMED DECISIONS THAT THEY BELIEVE ARE IN THEIR BEST INTEREST WITH RESPECT TO FAMILY PLANNING
- TO PROVIDE EDUCATION, TESTING AND INFORMATION FOR THE GENERAL PUBLIC
- SERVE AS THE COODINATING CENTER FOR THE NEWBORN HEMOGLOBINOPATHY SCREENING PROGRAM FOR THE MDHHS



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PROPHYLAXIS WITH ORAL PENICILLIN IN CHILDREN WITH SICKLE CELL ANEMIA

A Randomized Trial

MARILYN H. GASTON, M.D., JOEL I. VERTER, PH.D., GERALD WOODS, M.D., CHARLES PEGELOW, M.D.,
JOHN KELLEHER, M.D., GERALD PRESBURY, M.D., HAROLD ZARKOWSKY, M.D., ELLIOTT VICHINSKY, M.D.,
RATHI IYER, M.D., JEFFREY S. LOBEL, M.D., STEVEN DIAMOND, M.D., C. TATE HOLBROOK, M.D.,
FRANCES M. GILL, M.D., KIM RITCHEY, M.D., AND JOHN M. FALLETТА, M.D.,
FOR THE PROPHYLACTIC PENICILLIN STUDY GROUP

Gaston et.al.

Landmark article paved the way for newborn screening

PENICILLIN STUDY

	<u>Penicillin</u>	<u>Placebo</u>
Total #	105	110
Deaths	0	3
Infection	2	13



Dear Ms. Jones:

Every child born in the state of Michigan is tested for sickle cell conditions. The test performed on your newborn indicates that he/she has sickle cell disease. Although the initial test is very reliable, a repeat test is required by the state.

I am a pediatrician with a special interest in sickle cell disease and would like to help you get your baby retested and provide your family with free educational sessions about sickle cell disease. We also provide routine medical care for children with sickle cell disease at the Sickle Cell Clinic at Children's Hospital. Please call me at (313)864-4406 at your earliest convenience. If I am not available please ask to speak to my assistant

INITIAL PHONE CONTACT

- Verify that she received the letter
- Trait status of both parents
- Aware of risk?
- Parental testing if FS – non paternity issue
- Know anyone with SCD (then vs now - variability)
- Infants pediatrician
- Infants insurance
- Need for repeat test
- Fever/Penicillin
- Pain
- Fetal Hemoglobin
- Educational Sessions
- Medical Referral
- Contact information
- Offer encouragement (not false hope)



Name _____

Type of sickle cell diseases

- _____ SS
- _____ SC
- _____ S Thal Zero
- _____ S Thal Plus

Usual Hemoglobin Level _____



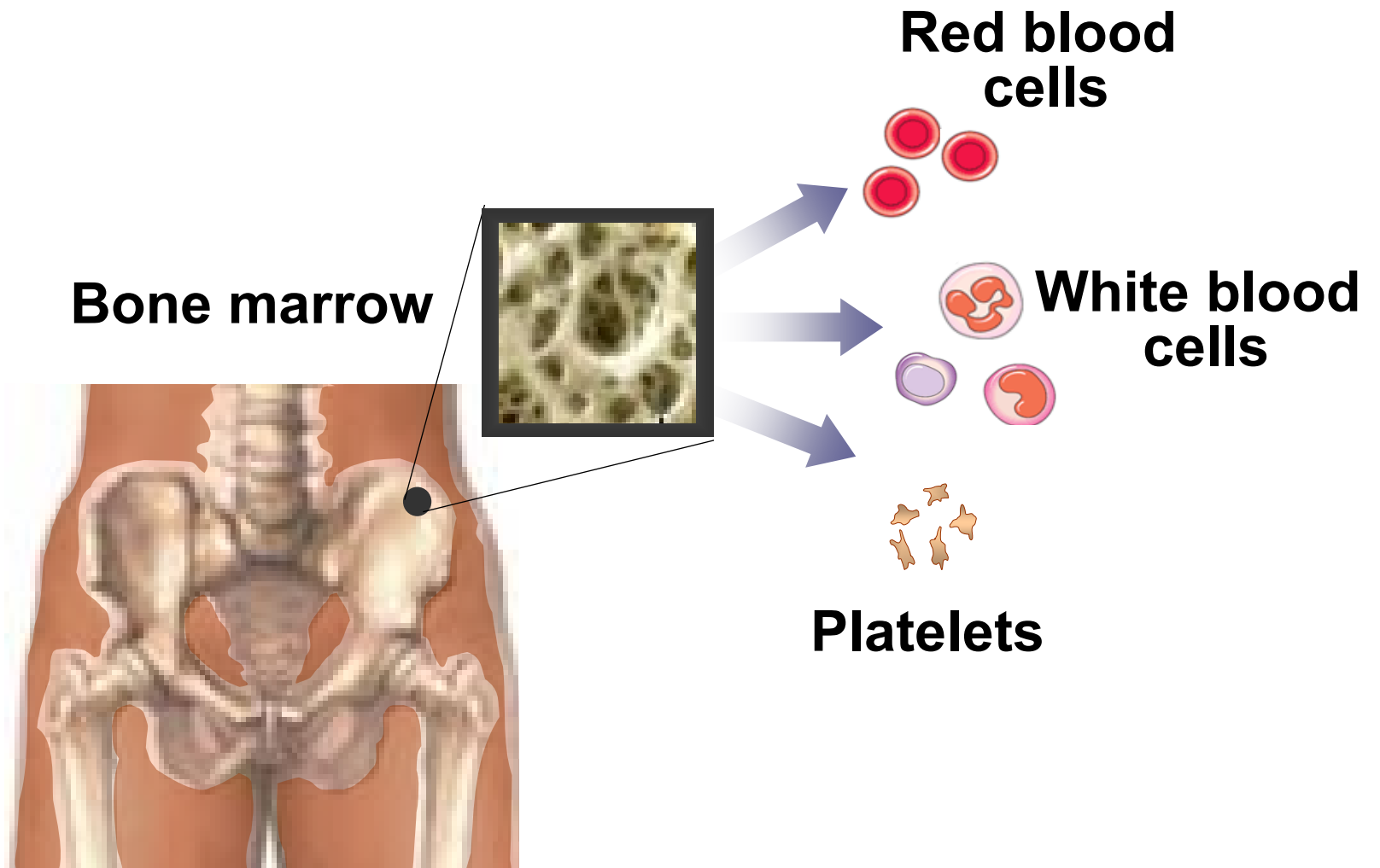
OUTLINE

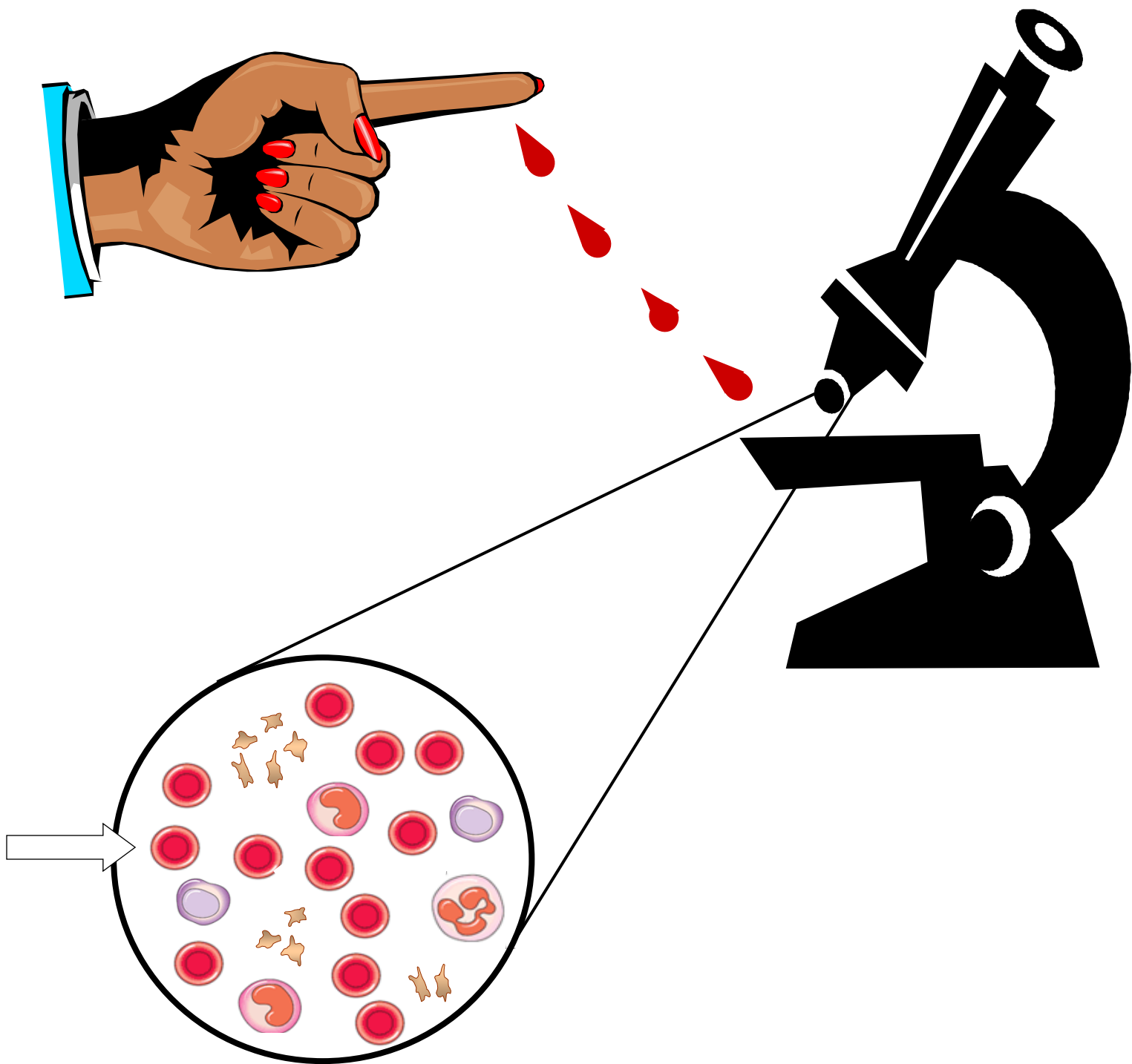
First session:

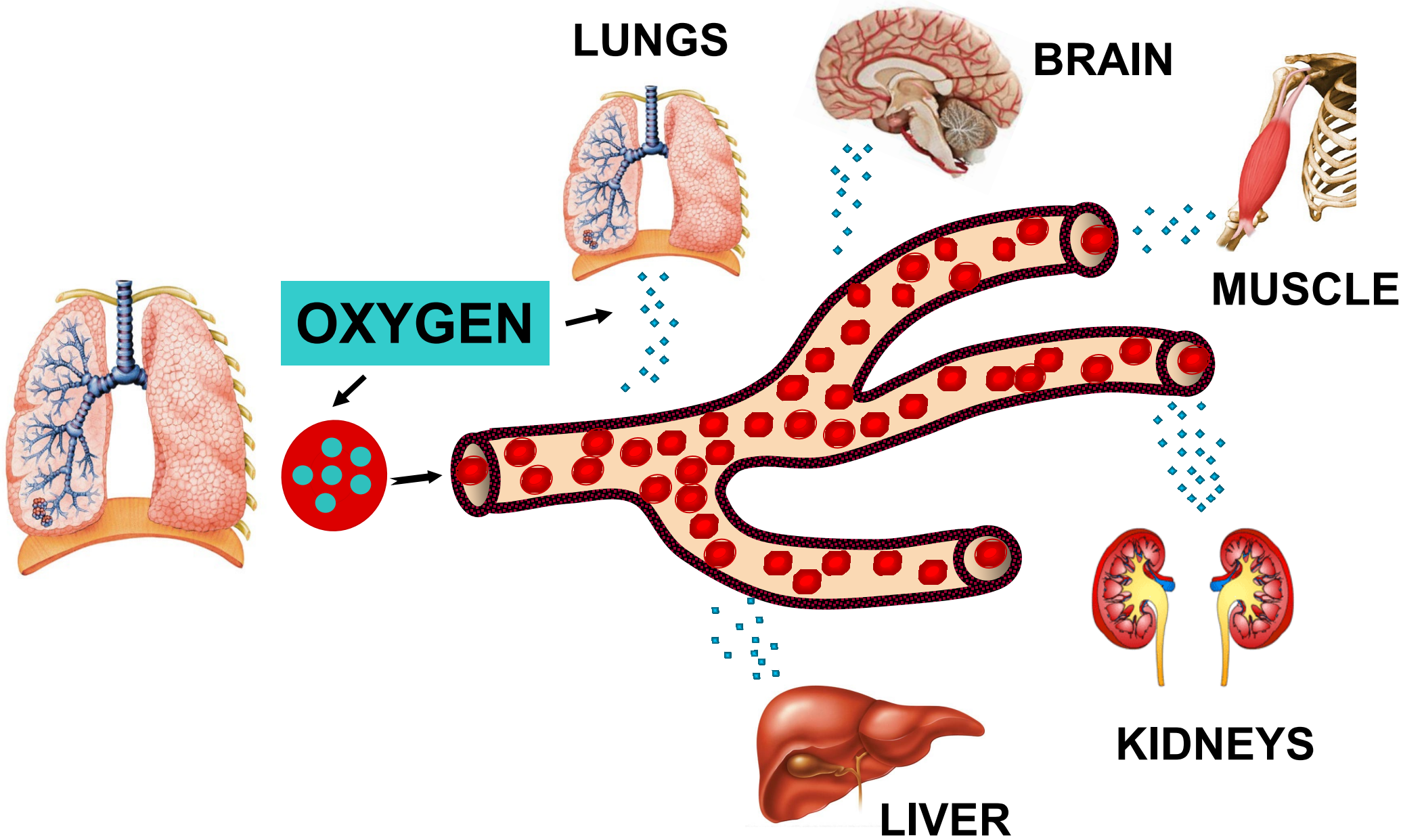
- What is SCD
- Health problems that occur early
- SCT vs SCD

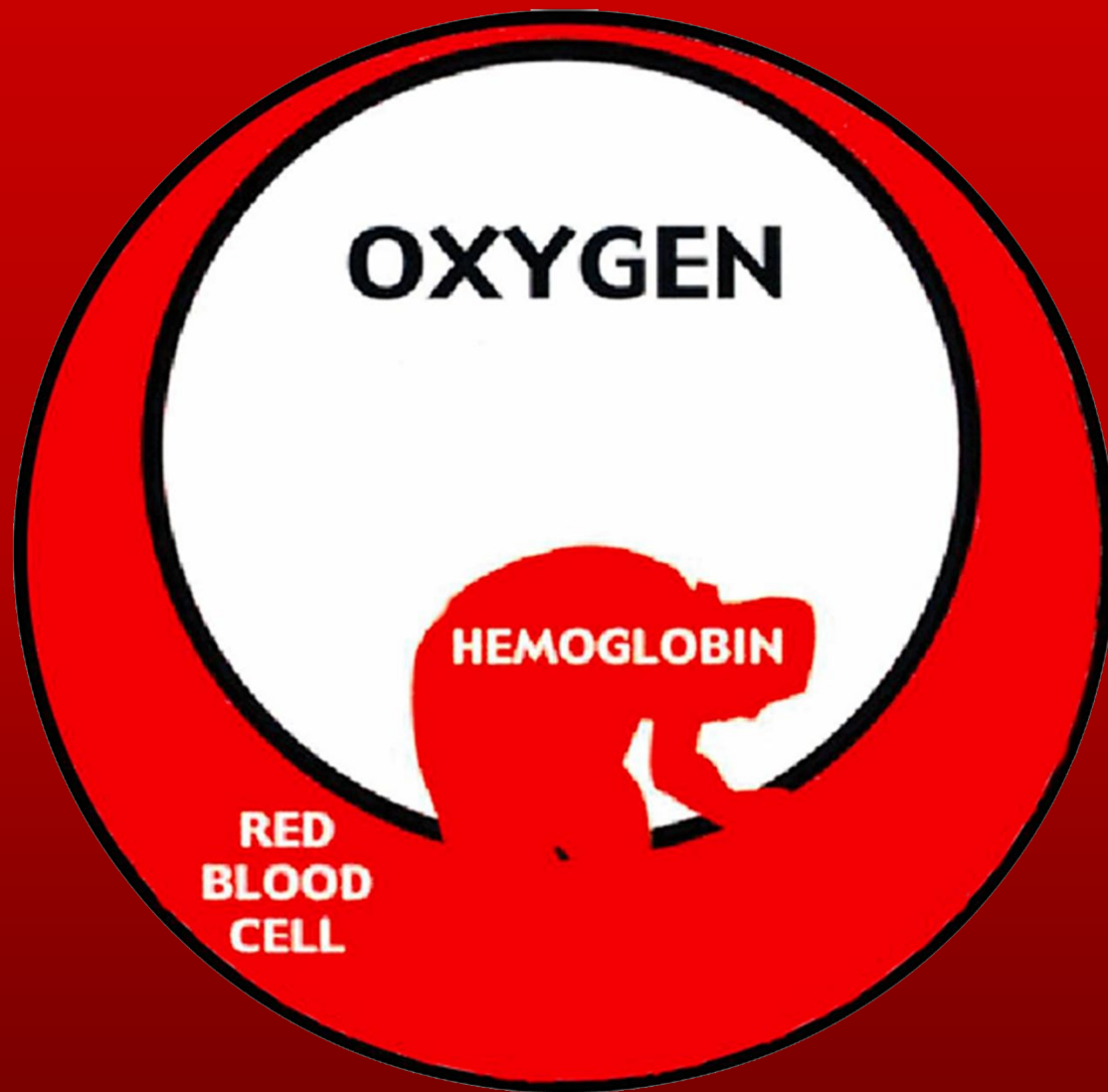
Second Session:

- How do you get SCD
- Different Types of SCD
- Why is it more common in Black People
- Good News (Research Update)

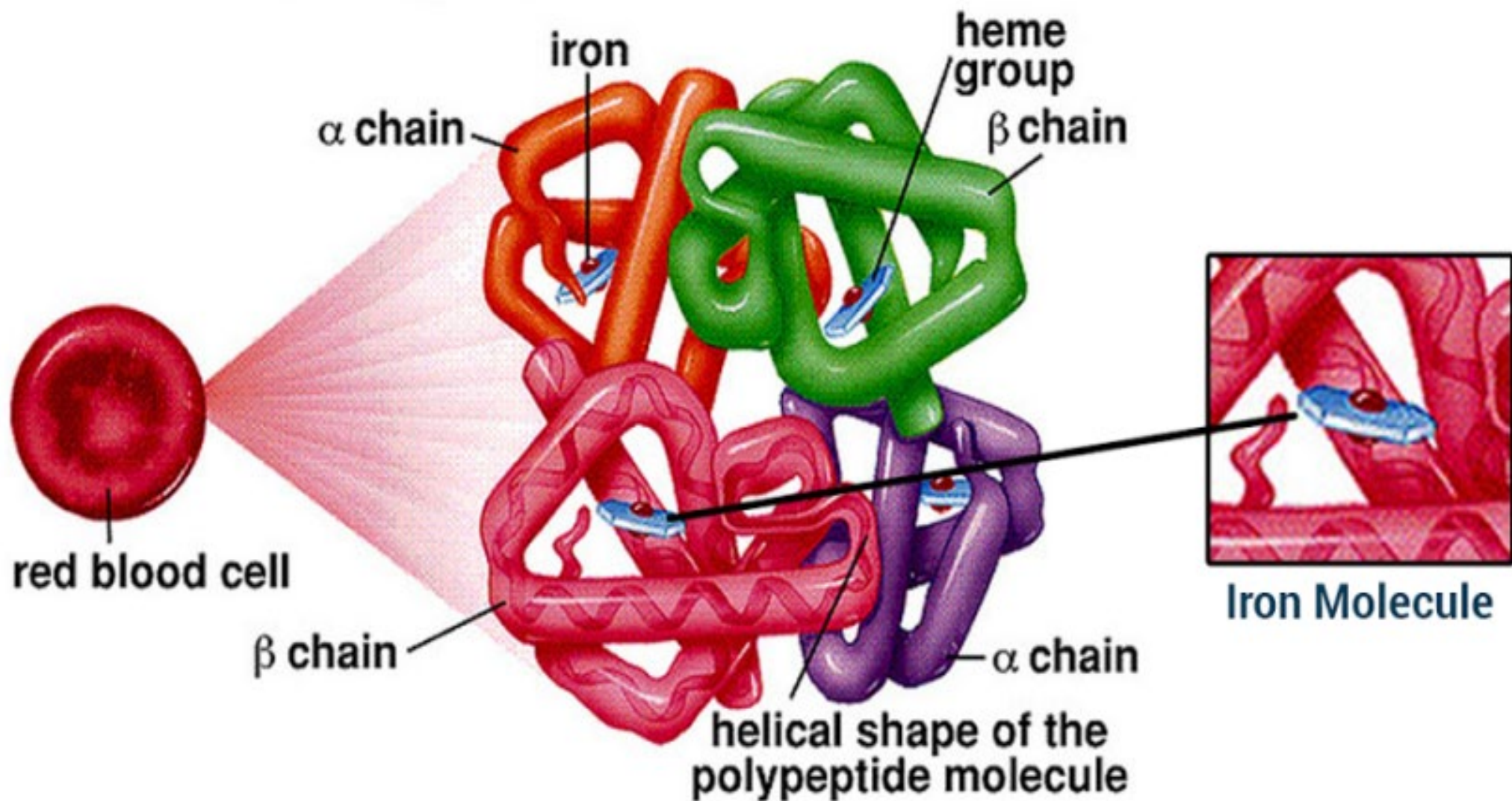








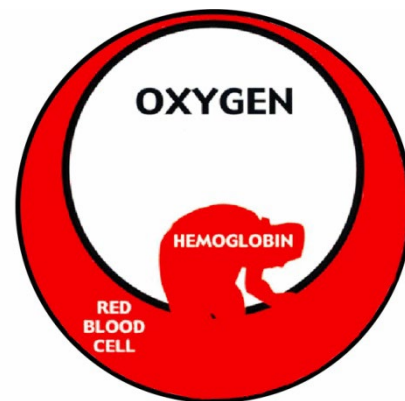
HEMOGLOBIN

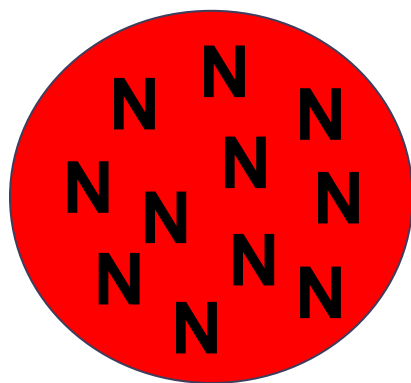


NORMAL HEMOGLOBIN

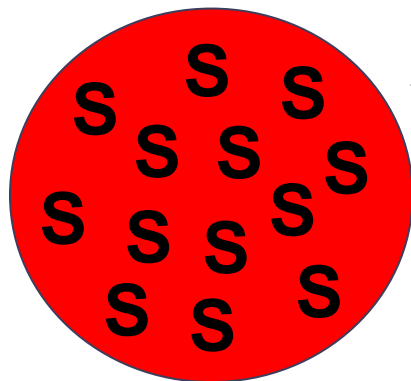
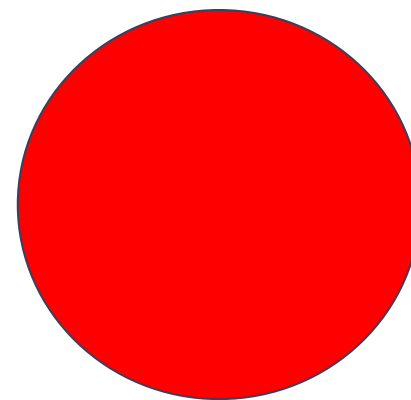
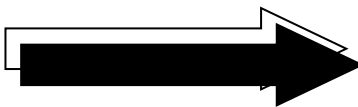
SICKLE HEMOGLOBIN

HEMOGLOBIN C

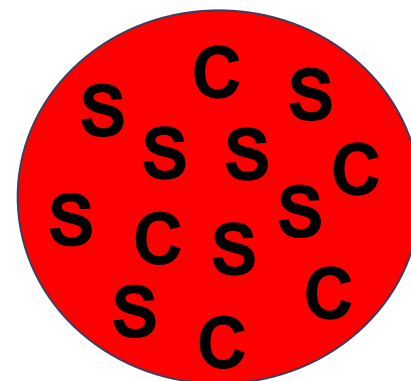
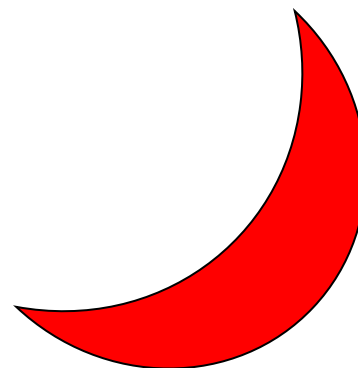
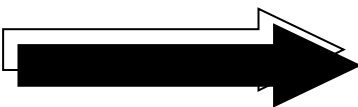




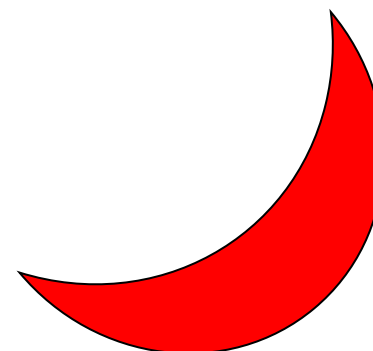
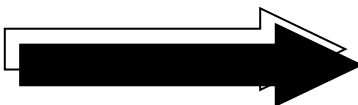
O_2



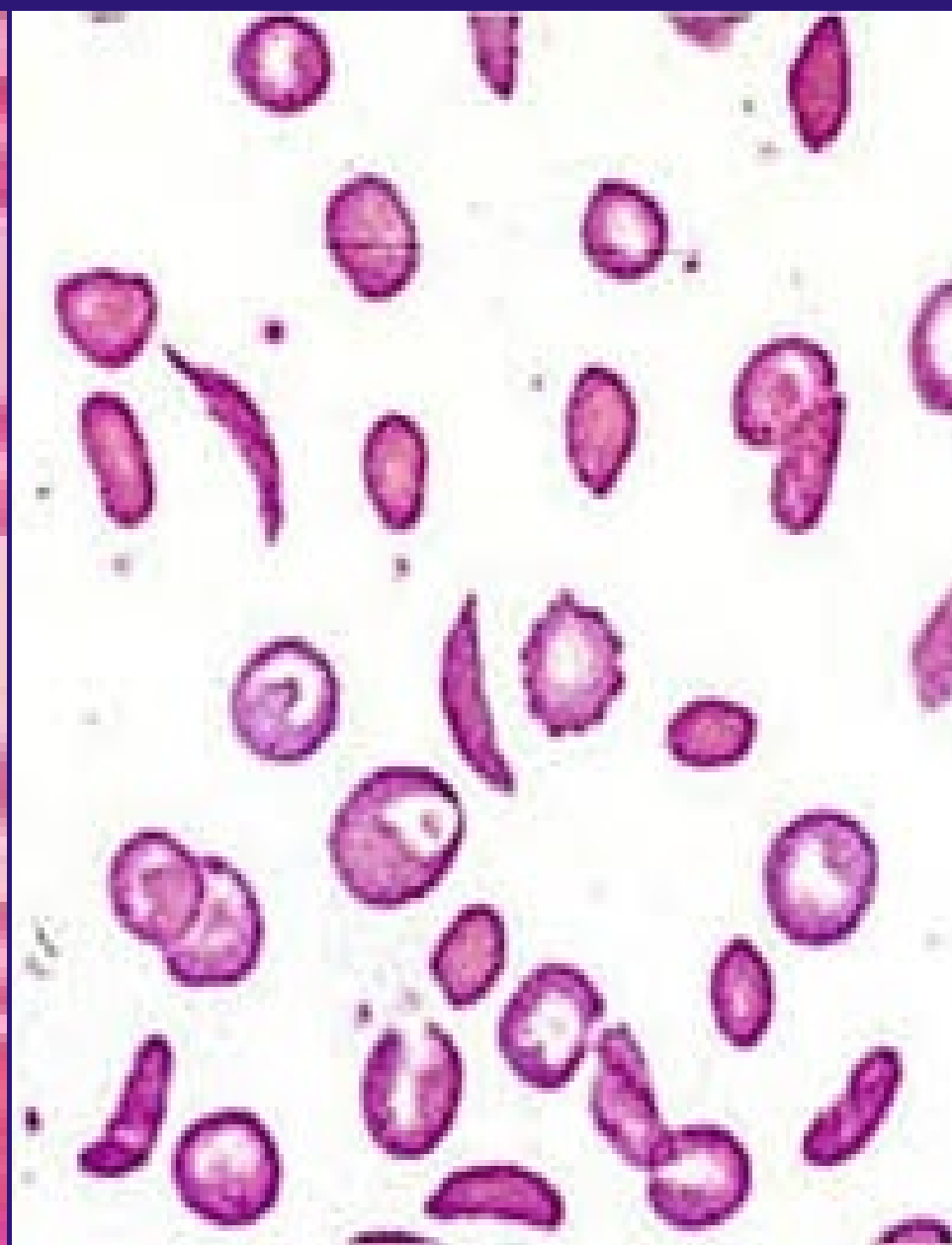
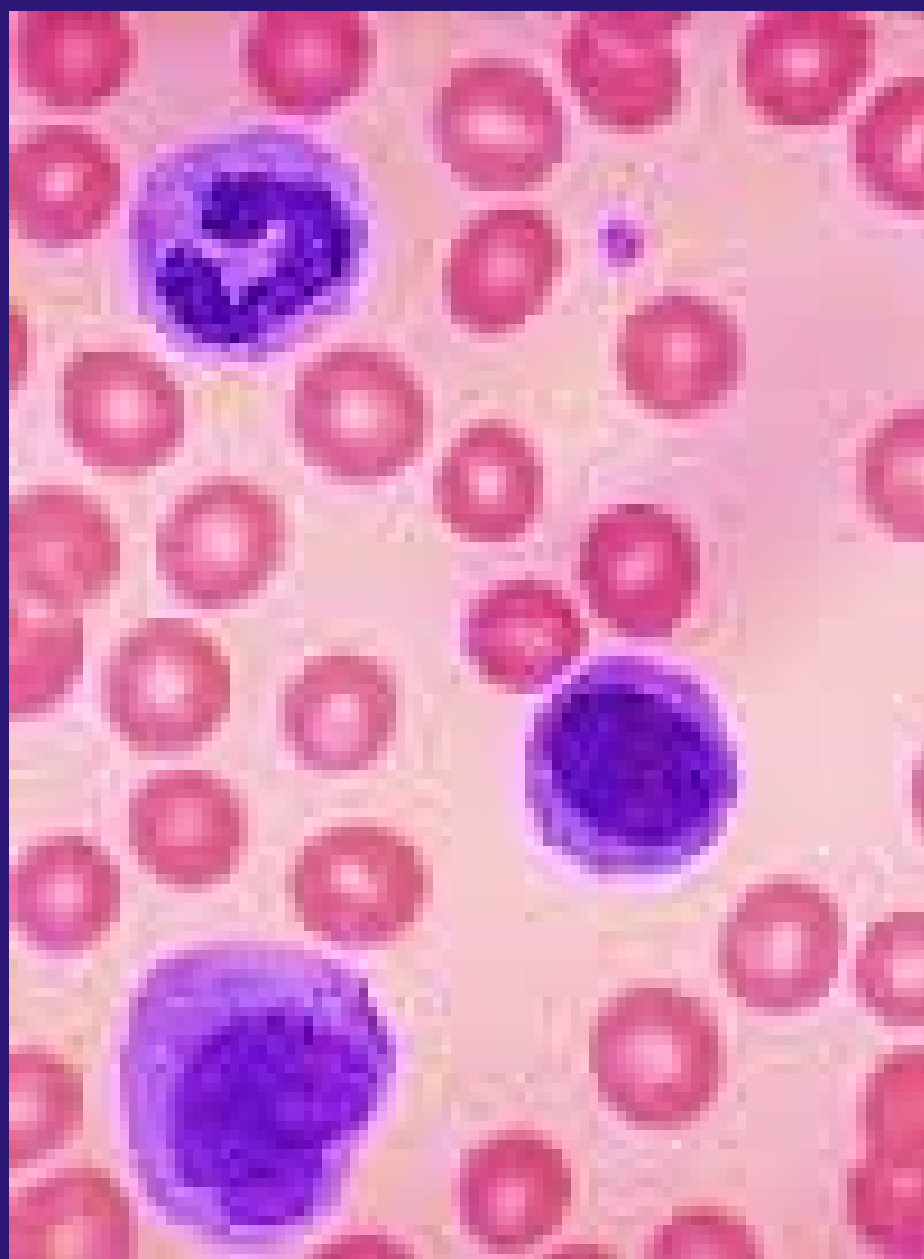
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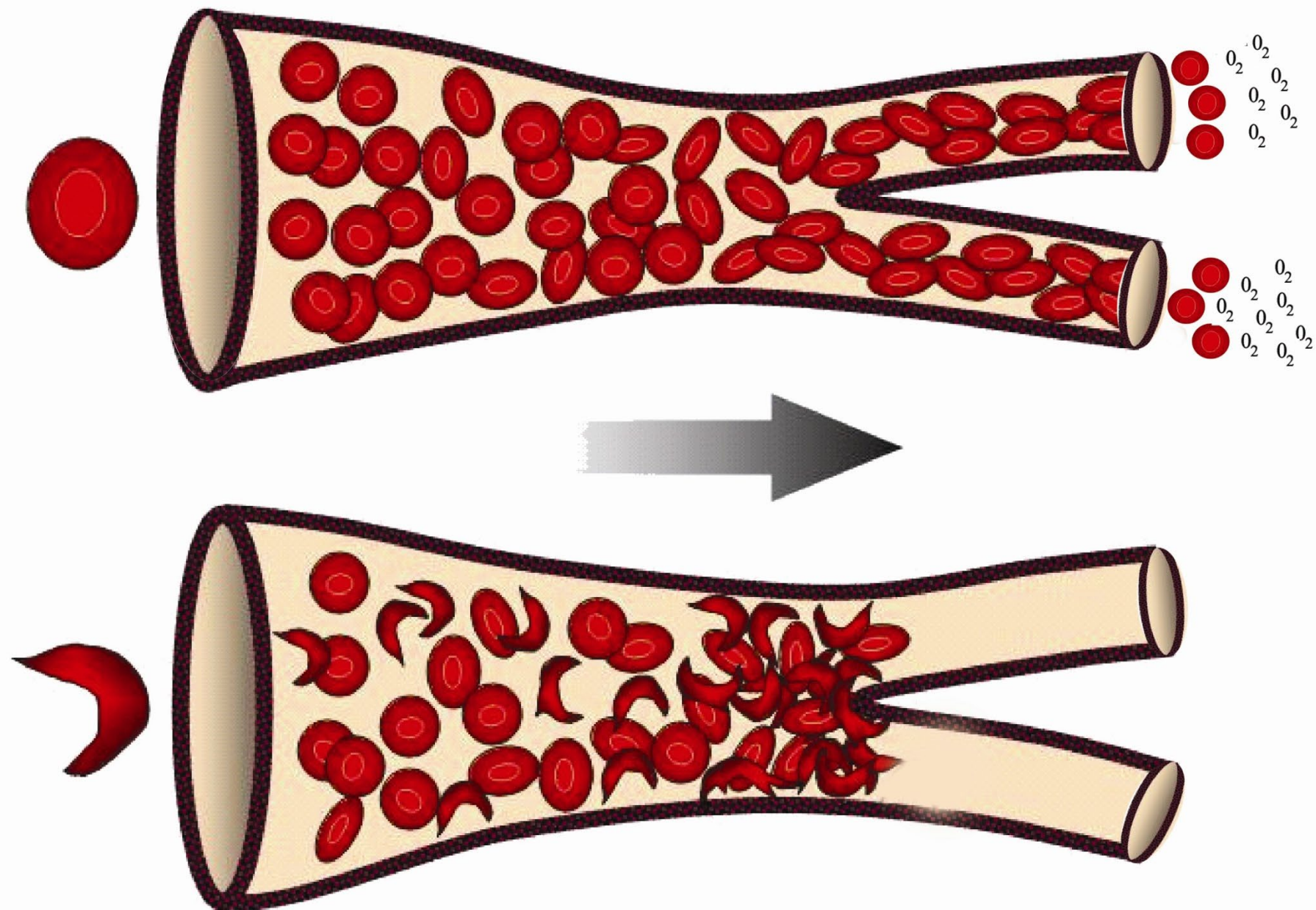
O_2







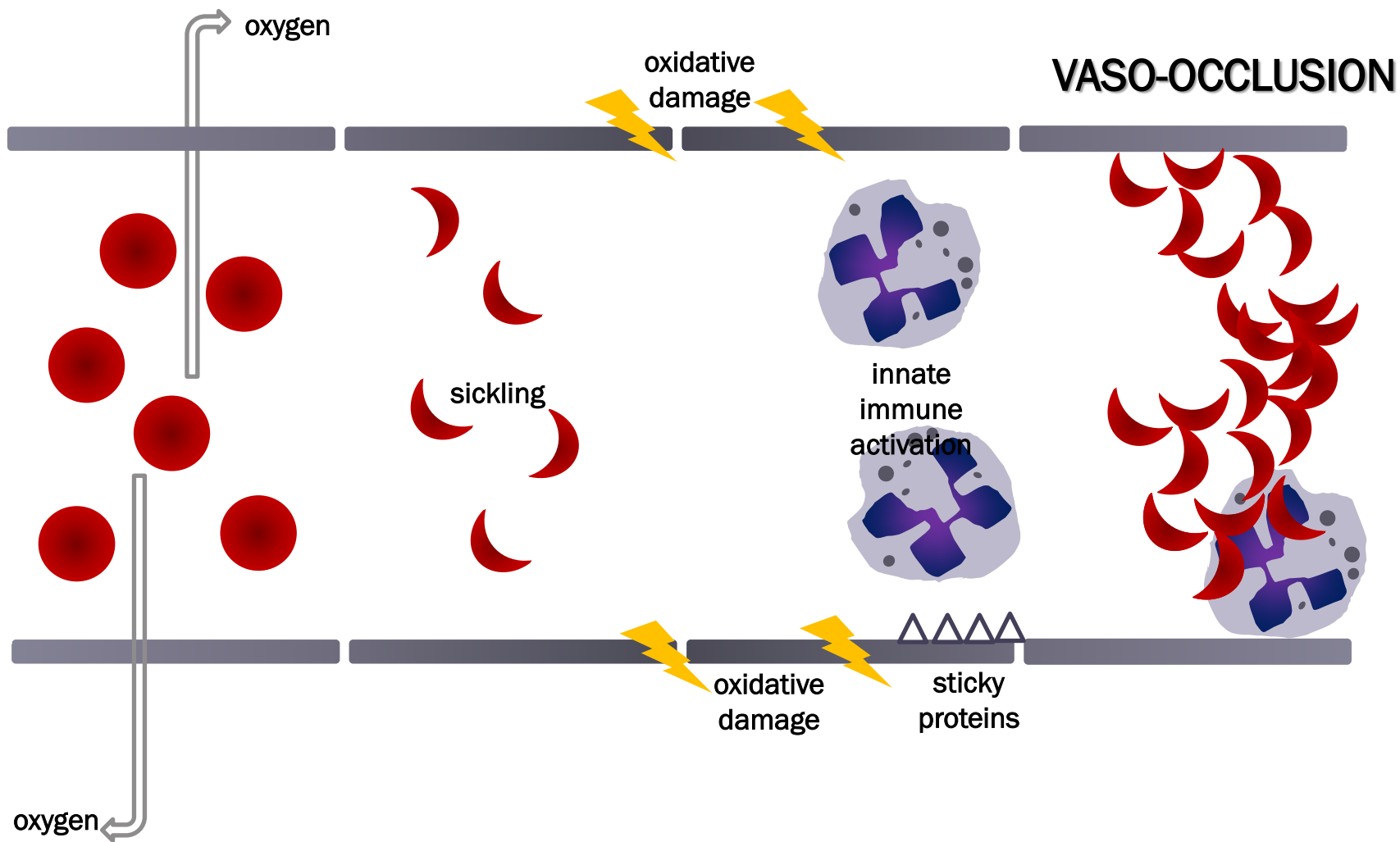


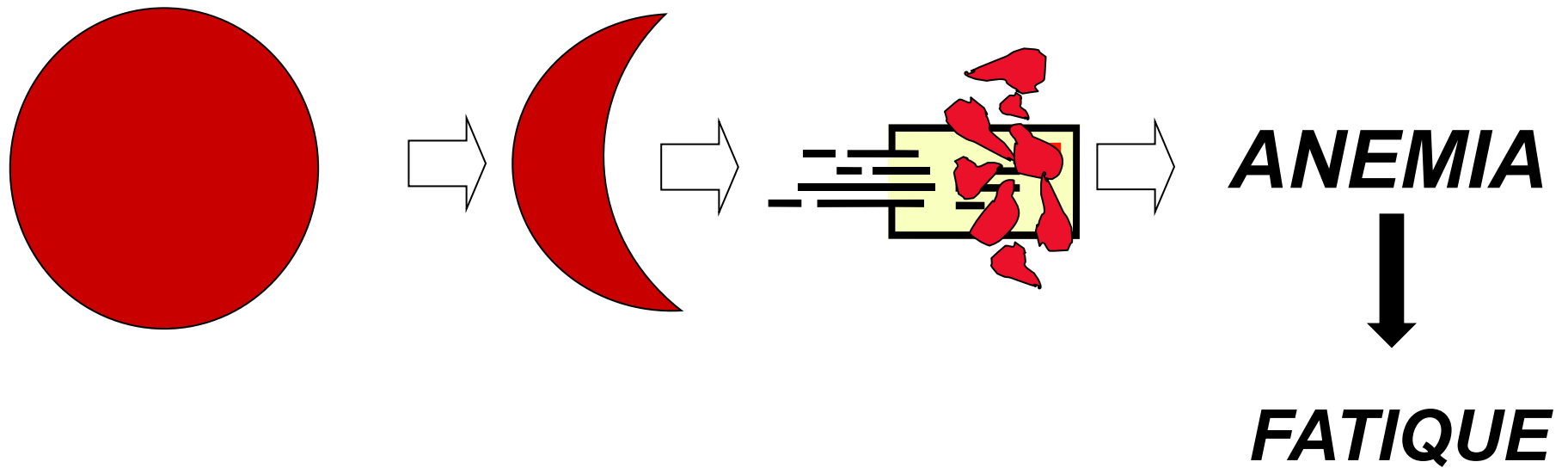
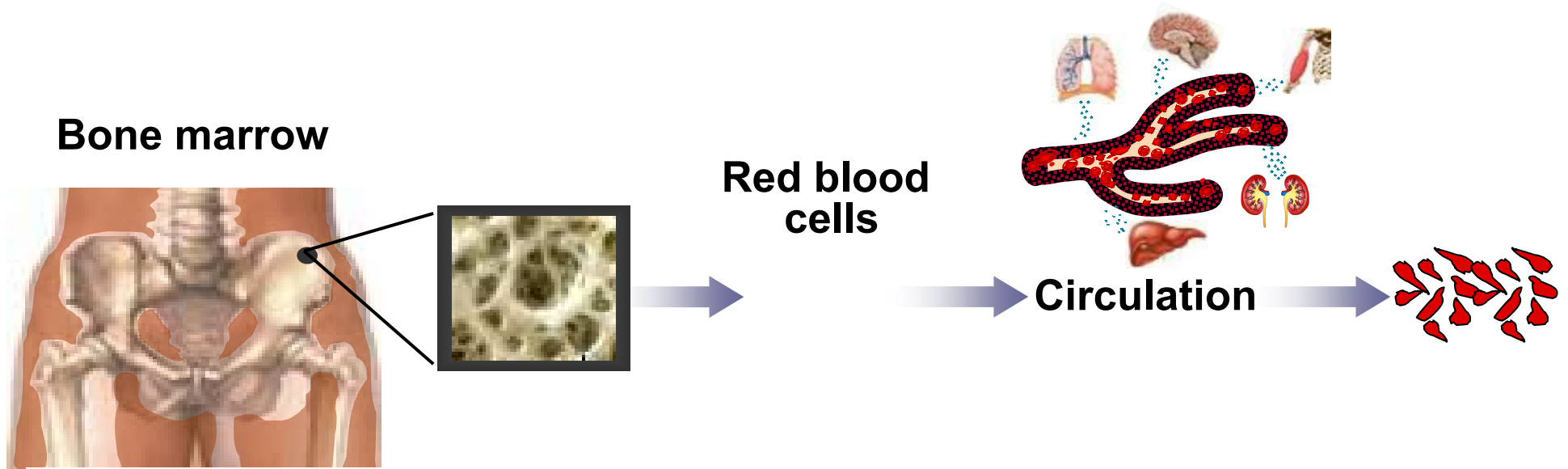


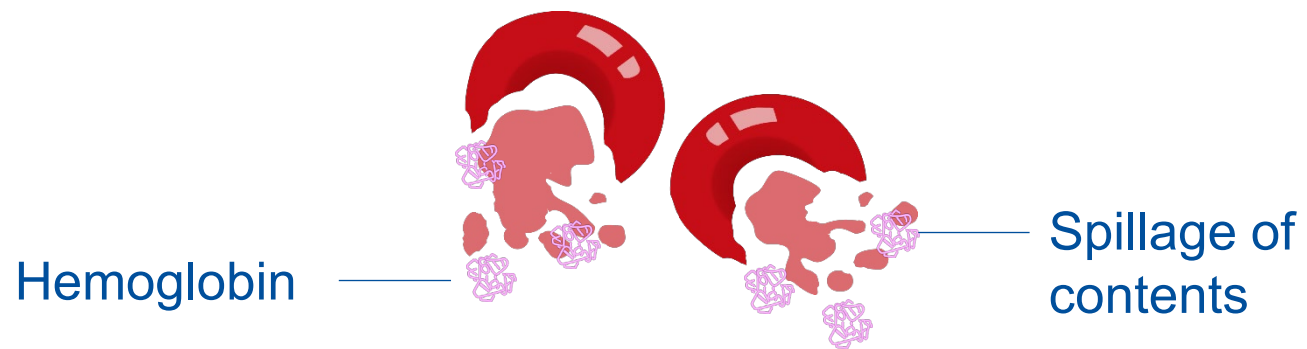
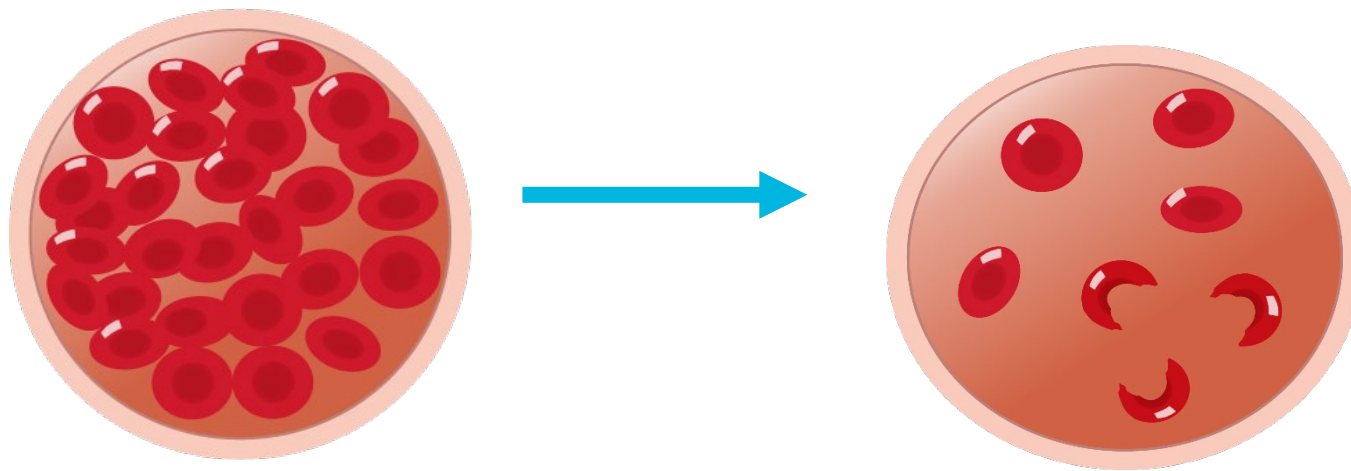


Pain

*Organ
Damage*



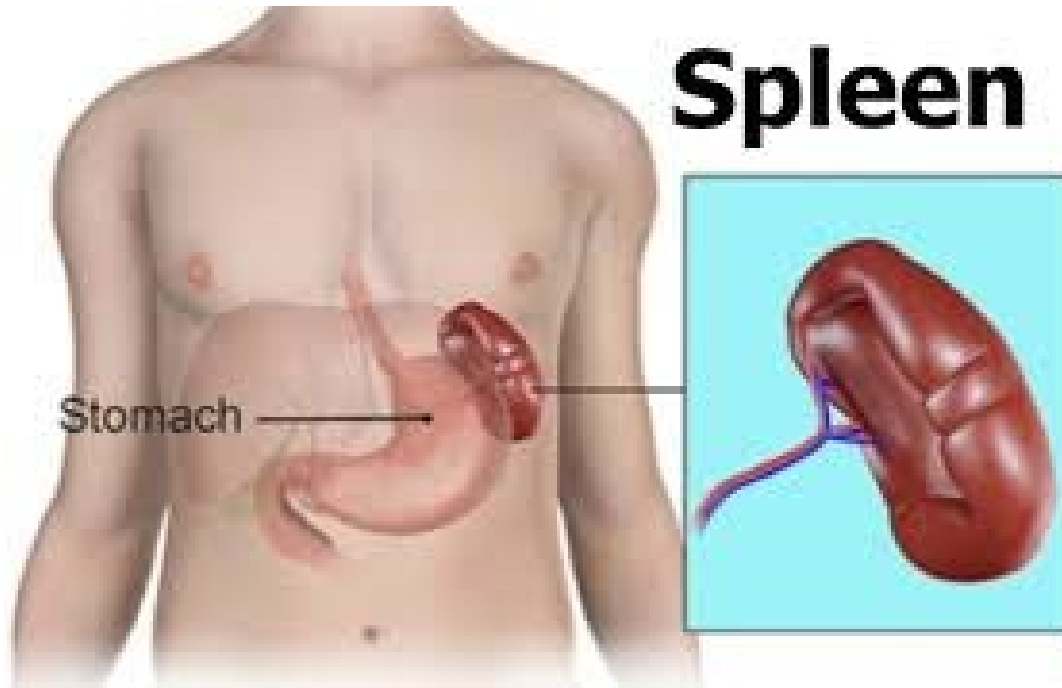




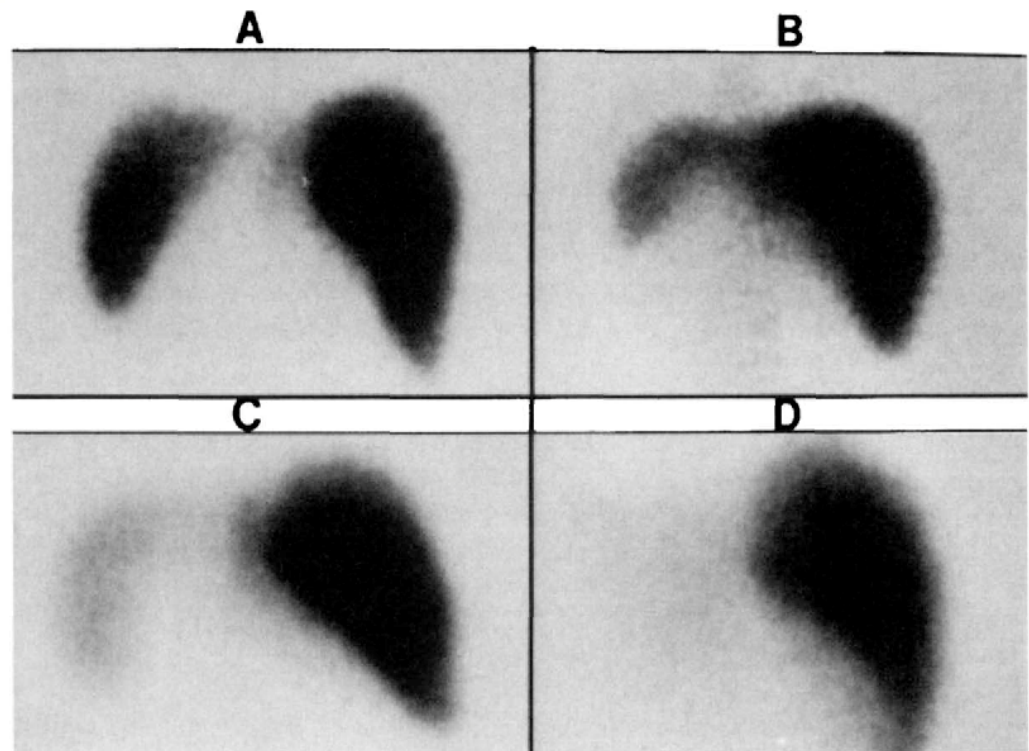




ONE DAY AT A TIME

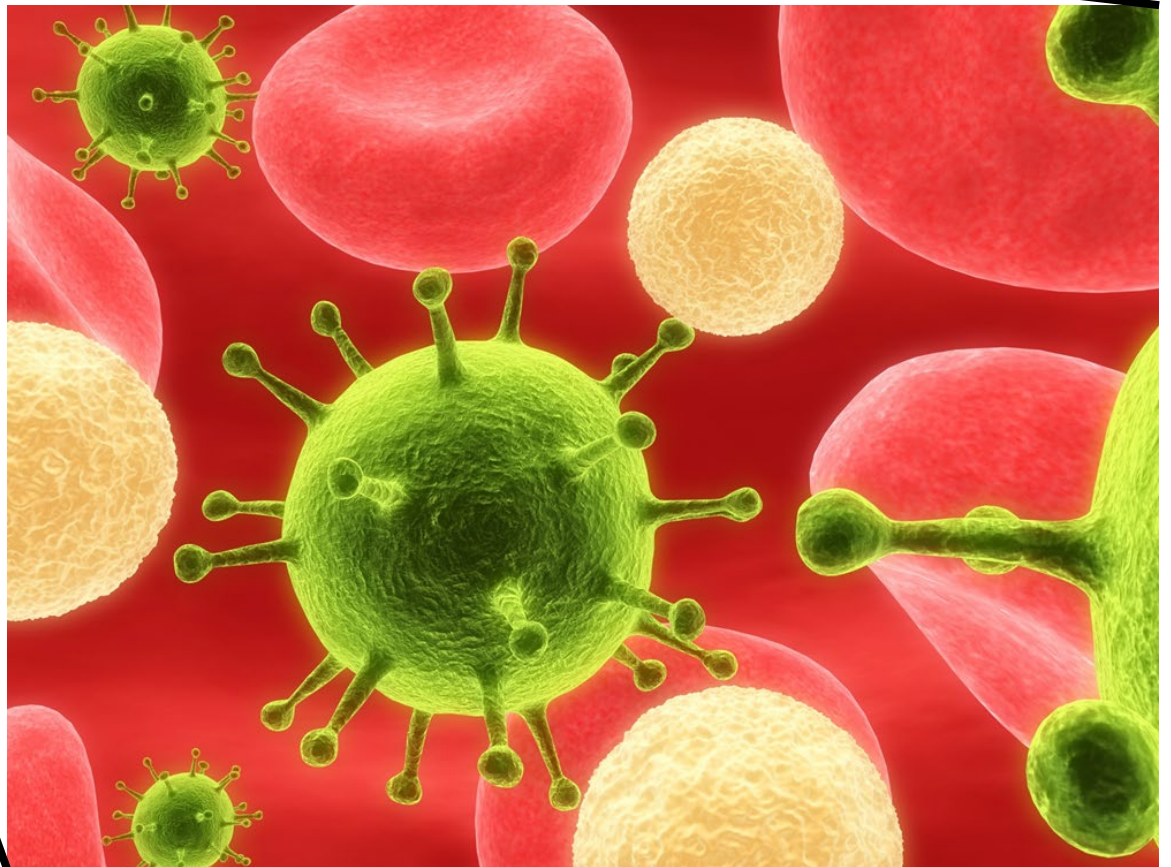


**Spleen
Scan**

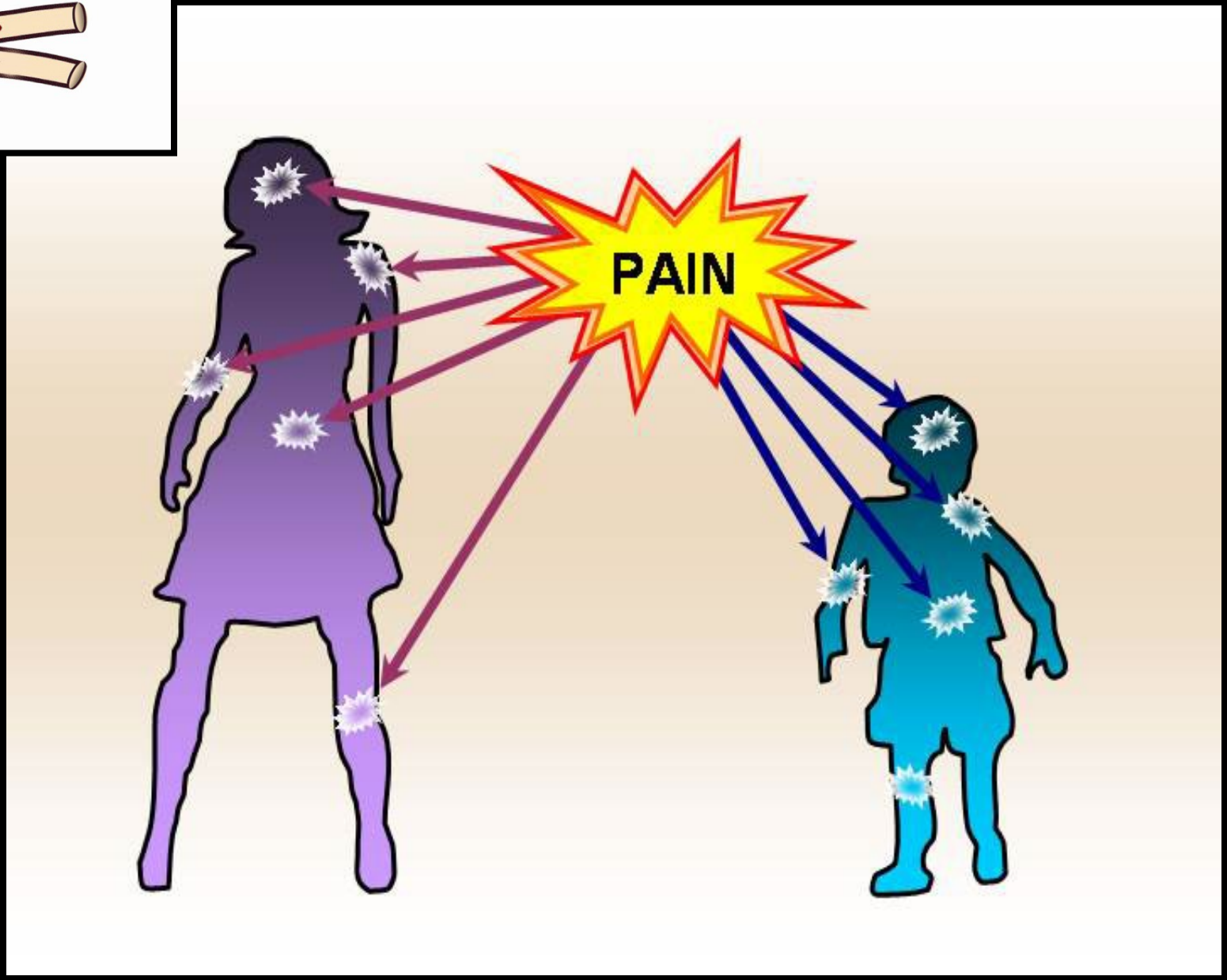
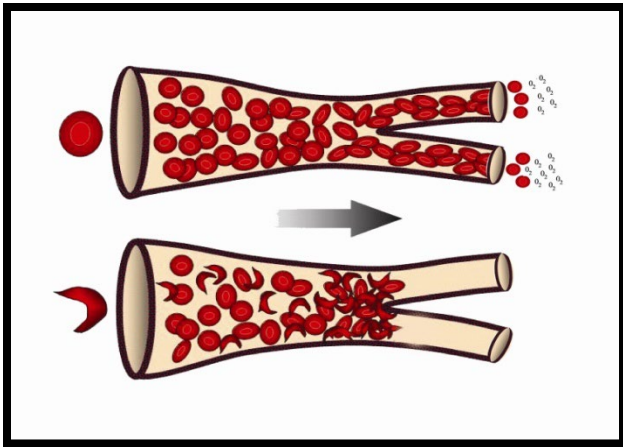


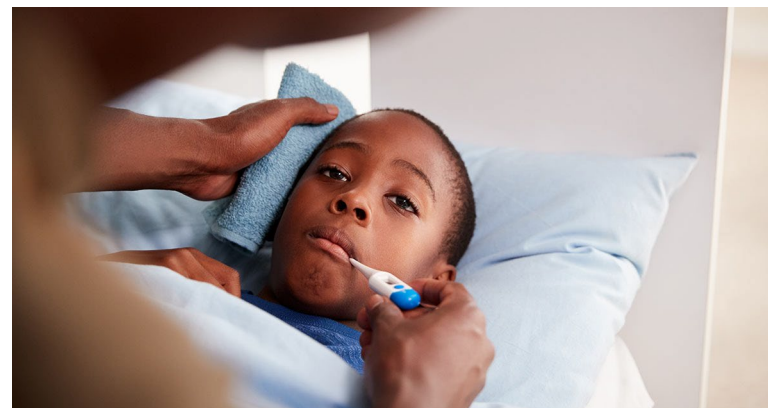
INFECTION

**Strep
Pneumo**

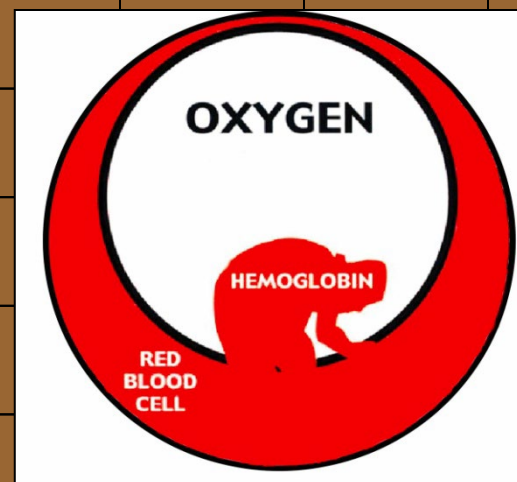
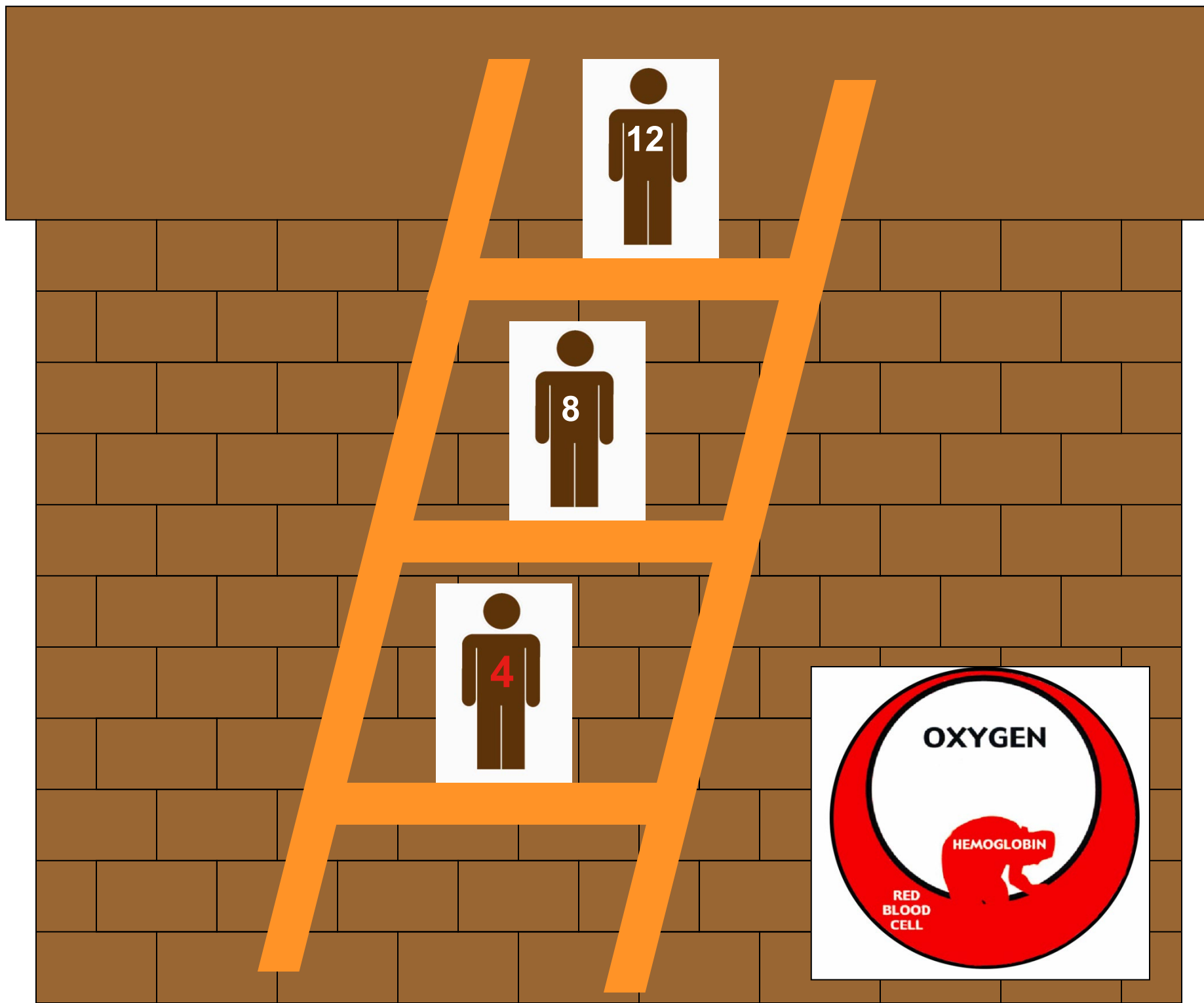


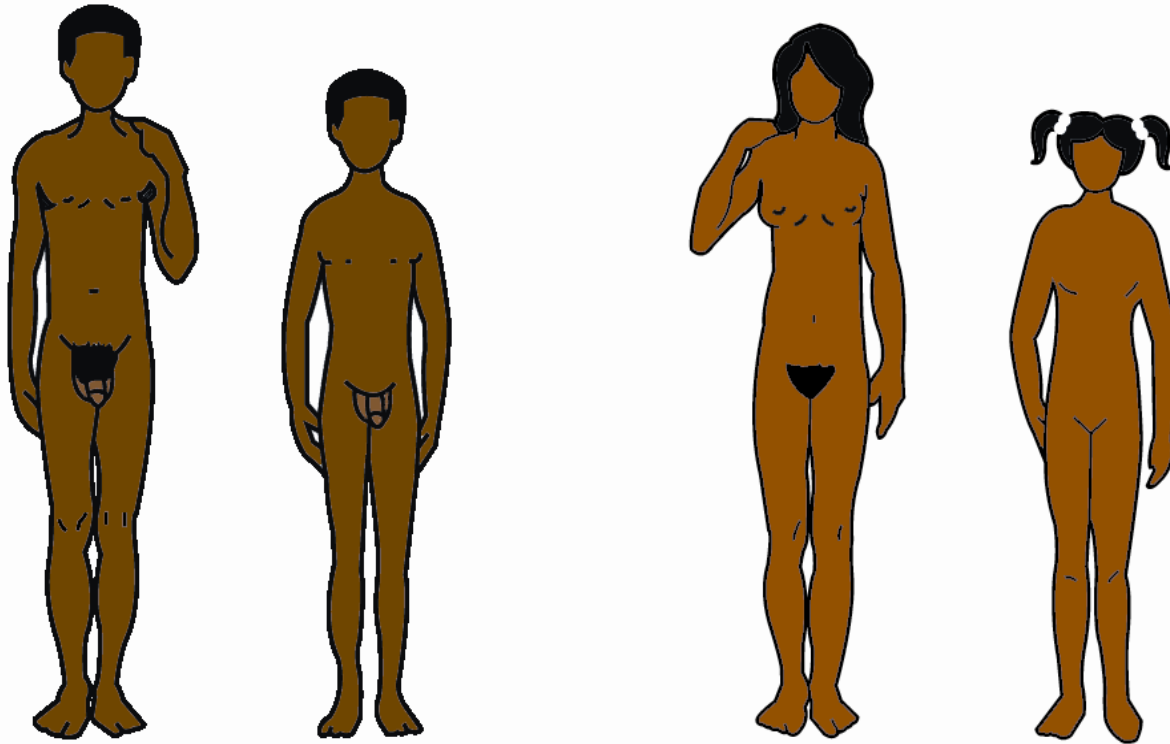
Bacteria



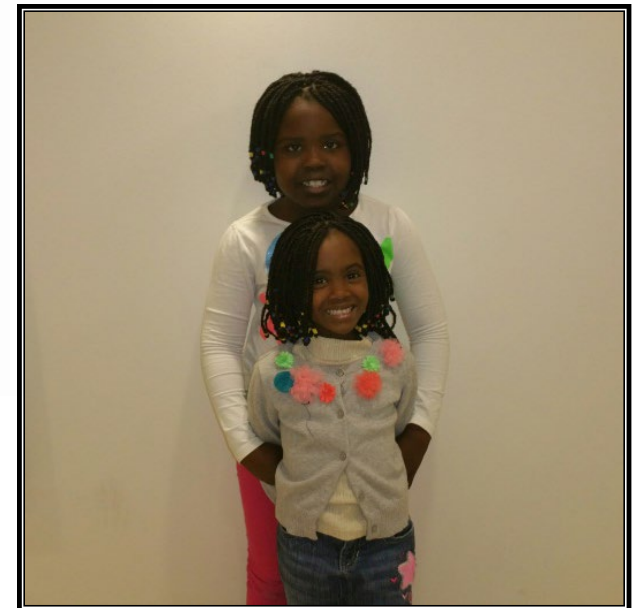


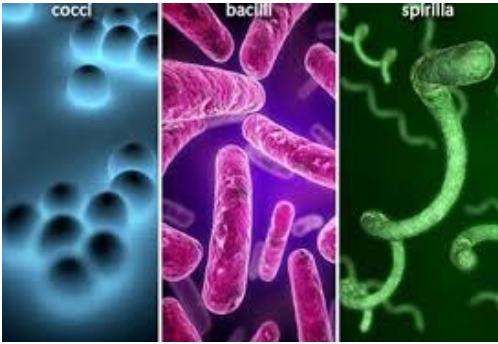
Routine Immunizations:
Pevnar 13
Meningococcal
Influenza





DELAYED GROWTH AND PUBERTY





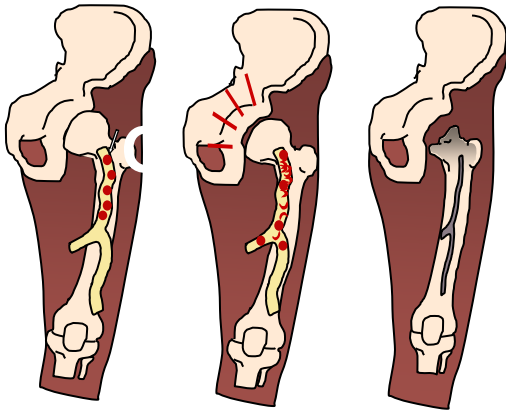
Infection, increased susceptibility to COVID19



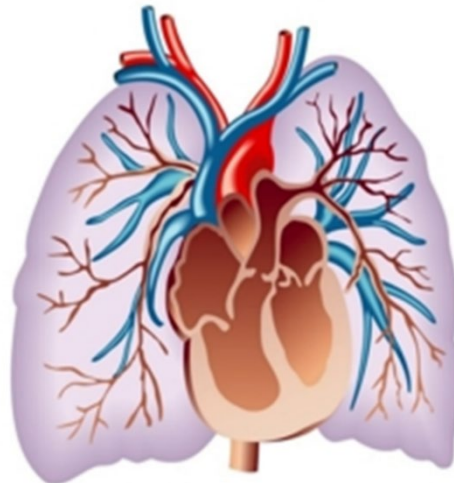
Yellow Jaundice



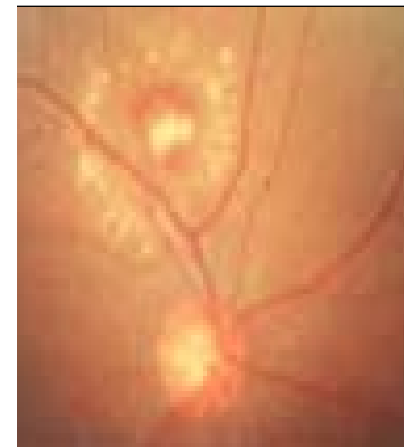
Gallstones



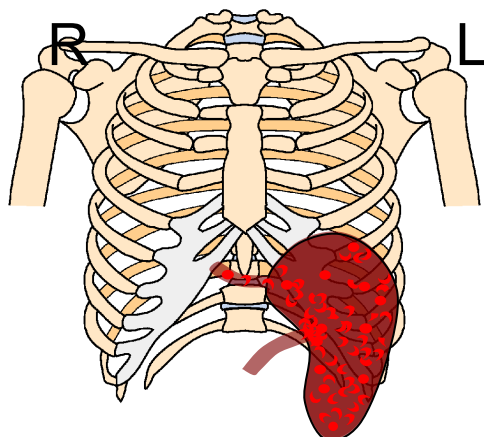
Avascular necrosis AVN



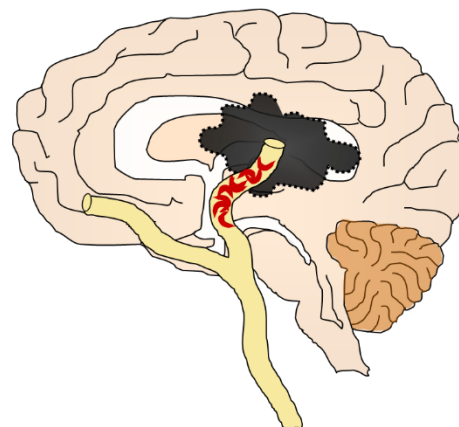
Pulmonary Hypertension



Retinopathy



Splenic sequestration



Stroke

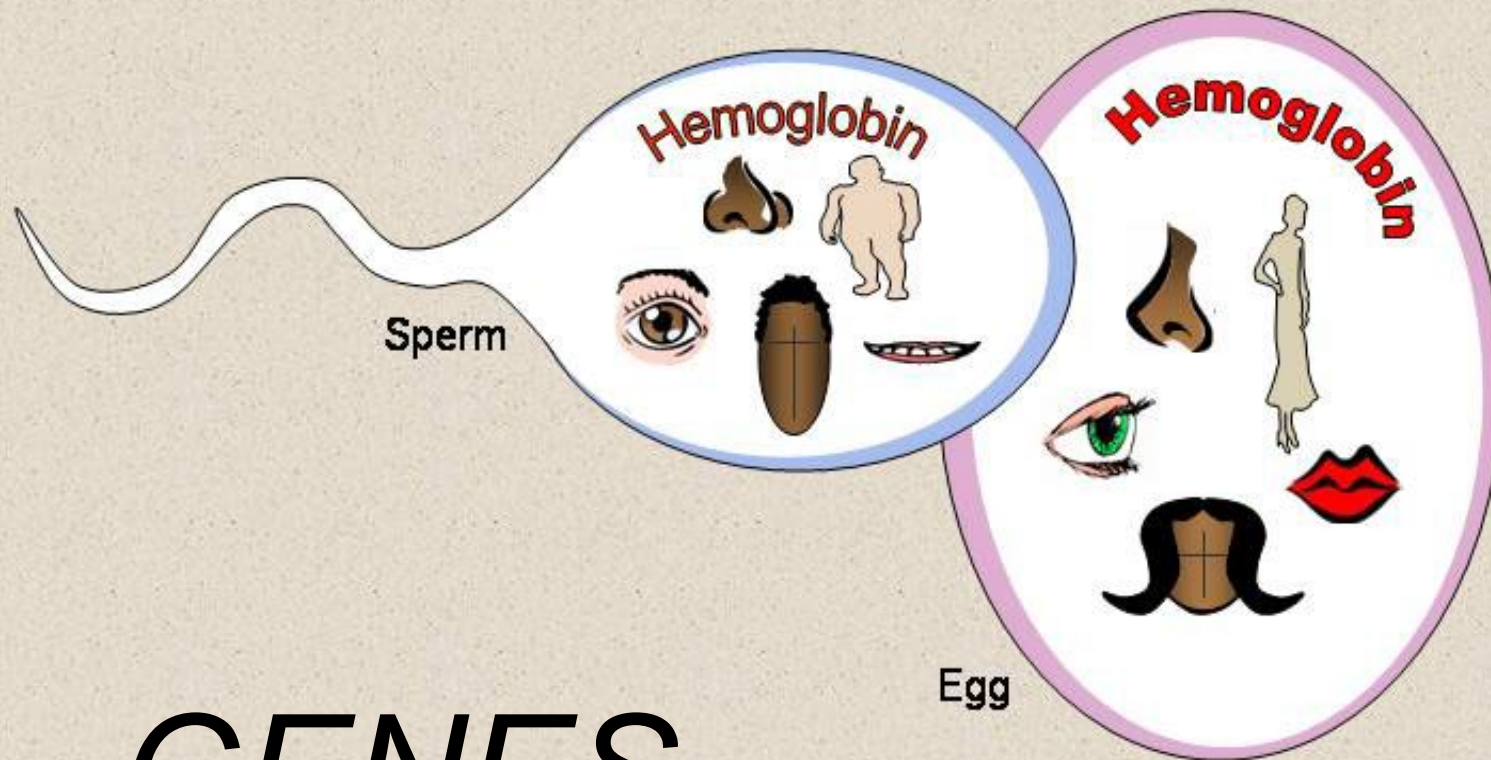


Acute Chest Syndrome



Leg Ulcers

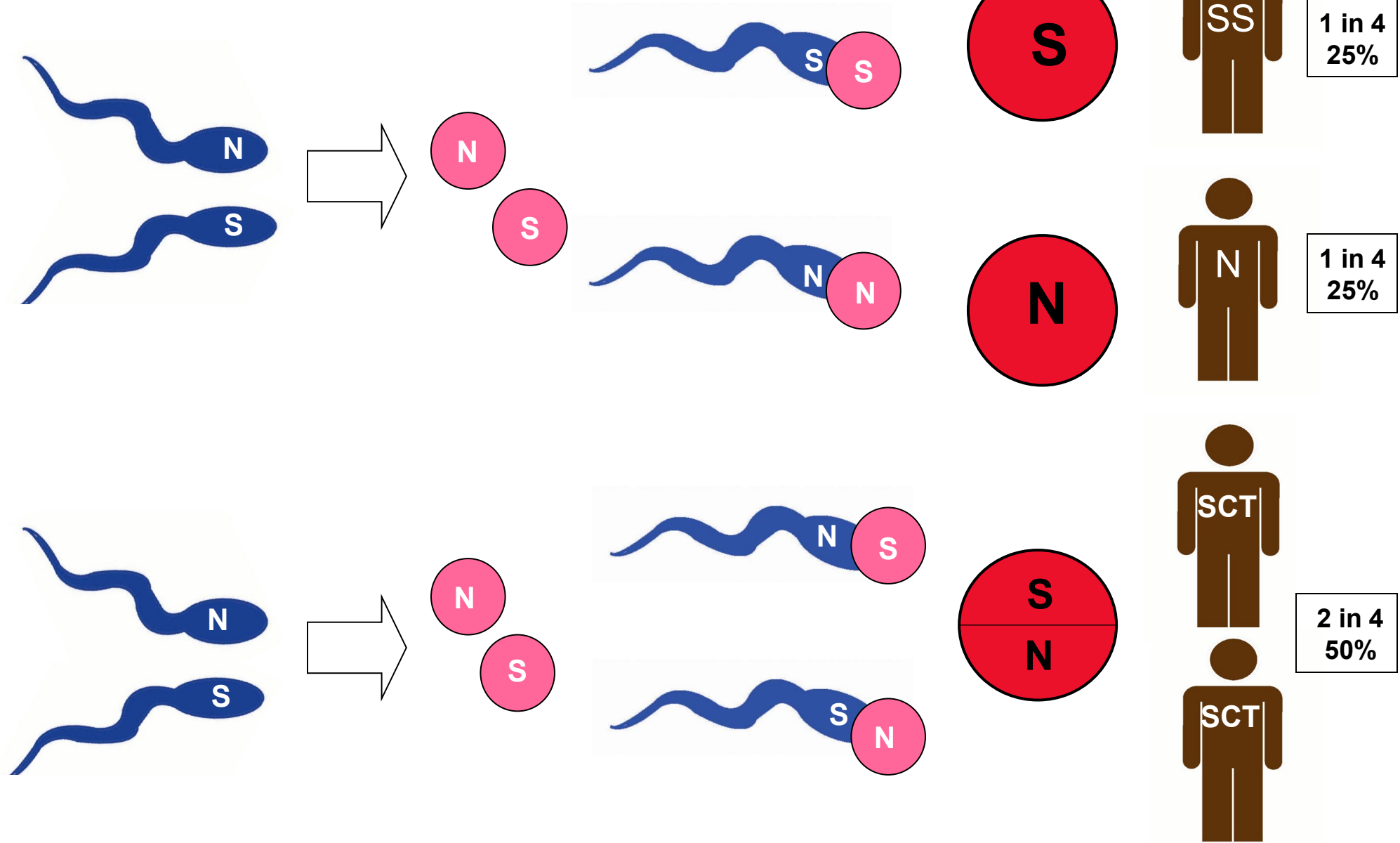
Inherited Characteristics



**Father
SICKLE CELL
TRAIT**

**Mother
SICKLE CELL
TRAIT**

Children



1 in 4

**Sickle Cell
Trait**

+

**Sickle Cell
Trait**

=

**Sickle Cell
Anemia SS**

**Sickle Cell
Trait**

+

**Hemoglobin
C Trait**

=

**Hb SC
Disease**

**Sickle Cell
Trait**

+

**Thalassemia
Trait**

=

**Sickle
Thalassemia**

**No
Children**



Adoption

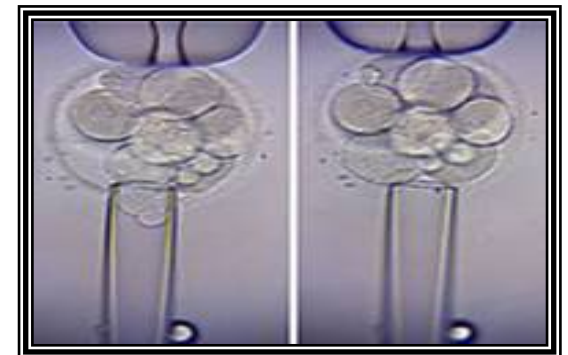
OPTIONS

Prenatal diagnosis

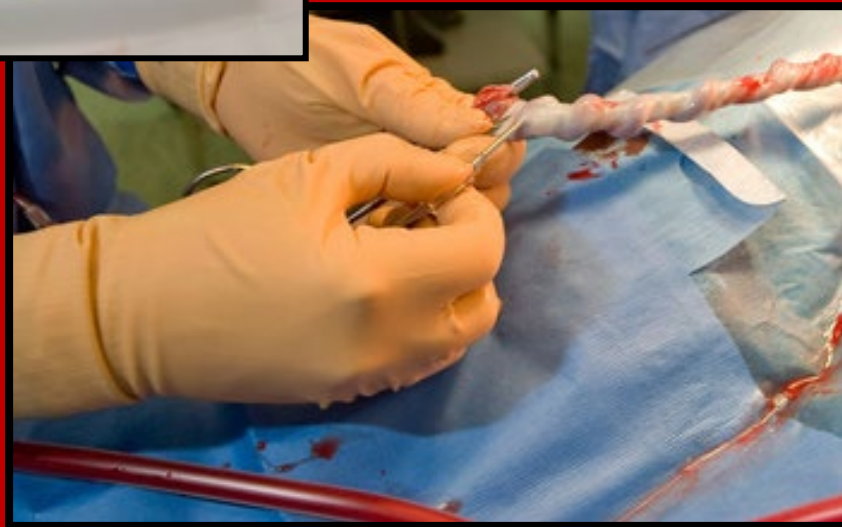


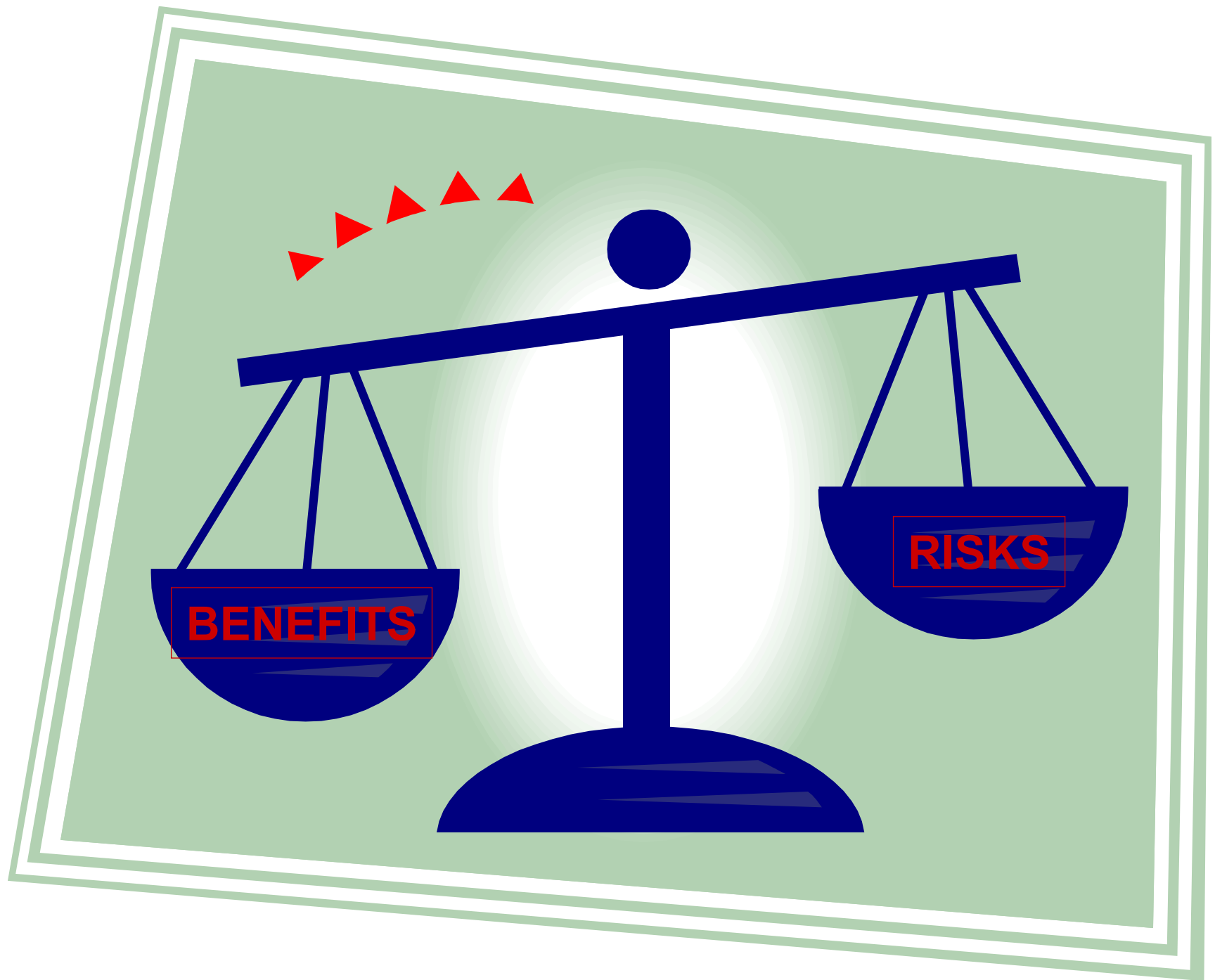
**Amniocentesis
CVS**

**Preimplantation
genetic
diagnosis**



CORD BLOOD STORAGE

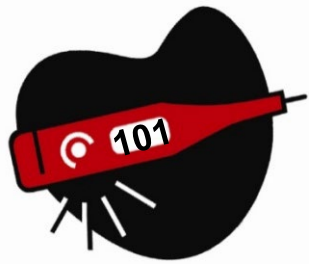




Remember to:



Give penicillin twice a day until age 5



Treat fever as an emergency
101 under the arm



For pain **not** fever



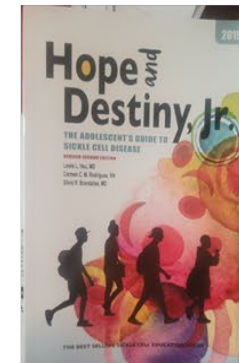
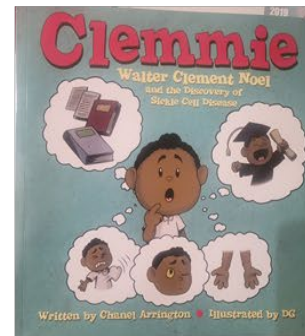
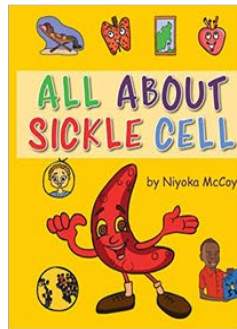
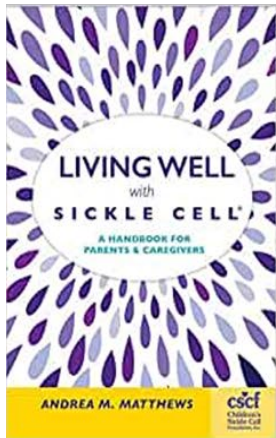
Get the pneumovax
vaccine 1st dose 2 year old

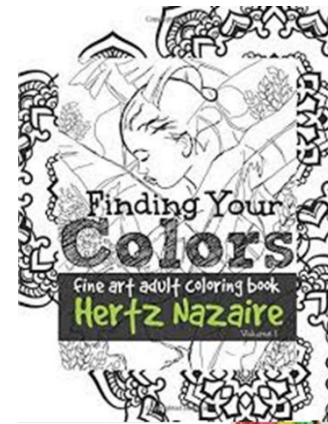
CHALLENGES PATIENTS FACE

- Young people don't know their trait status
- For 20 years only one disease modifying medication
- No universal cure
- Pediatric vs adult care “sickler”
“drug seeker”
- Limited mental health resources



Lifespan Approach to Education





ABOUT REFLEXOLOGY

Reflexology is the application of pressure to areas on the feet, hands and ears. Reflexology is generally relaxing and may be an effective way to alleviate stress.

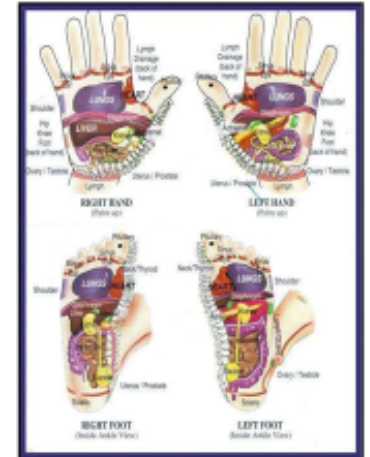
The theory behind reflexology is that these areas correspond to organs and systems of the body. Proponents believe that pressure applied to these areas affects the organs and benefits the person's health.

Reflexologists use foot charts to guide them as they apply pressure to specific areas. Sometimes these practitioners use items, such as rubber balls, rubber bands and sticks of wood, to assist in their work. Practitioners of reflexology include chiropractors, physical therapists and massage therapists, among others.

Several studies funded by the National Cancer Institute and the National Institutes of Health indicate that reflexology may reduce pain and psychological symptoms, such as anxiety and depression, and enhance relaxation and sleep. Studies also show that reflexology may have benefits in palliative care of people with cancer.

Reflexologists claim that reflexology also can treat a wide variety of medical conditions, such as asthma, diabetes and cancer. However, scientific evidence is lacking to support these claims.

Reflexology is generally considered safe, although very vigorous pressure may cause discomfort for some people.



DR. ROWLEY'S
**3-4-4 NUTRITIONAL METHOD
OF EATING**

For more information, contact Cayenne Wellness Center at www.cayennewellness.org : 818 377 5120

3-4-4 HAS MANY HEALTH BENEFITS

Benefits

Sickle Cell Disease

If you eat complex carbohydrates versus simple carbs, if you eat regular meals throughout the day, eat protein (but not too much) and healthy fats, you will do just fine.

3-4-4 and Sickle Cell

3-4-4 helps those with sickle cell disease. 3-4-4 is based on an eating plan rich in complex carbohydrates, protein and healthy fats (like olive oil). With 3-4-4, one eats three meals a day plus two snacks.

What You Need To Know About Sickle Cell and Diet

Research shows that children with SCD have decreased height and weight. Increased calories and protein needs, and deficiencies in zinc, folic acid, and vitamins A, C and E may factors.

WHAT IS 3-4-4?

Three-four-four (3-4-4) stands for breakfast - lunch - and dinner. Three (3) items to eat for breakfast, four (4) items to eat for lunch, and another four (4) items to eat for dinner. It is an eating plan that is based on obtaining all the vitamins, minerals, other nutrients and phytochemicals necessary for optimum health.

In order to achieve a diet that encompasses all of the above, 3-4-4 was created so that one would not have to think about what particular food provides vitamin K and what particular food source would one obtain potassium. By eating the 3-4-4 way,

you are guaranteed that each day, you have covered the gamut of all the food groups, vitamins and minerals.

How Can I Get Started on 3-4-4?

It's easy, really. 3-4-4 requires no special foods and has no hard to follow recipes. It requires eating 'real food':
Breakfast: dried fruit, fresh fruit and grain.
Lunch: fresh fruit, green vegetable, orange vegetable and protein/grain.
Dinner: Same as lunch

1. **What to eat.** Vitamin C (kiwi and oranges), Vitamin E (mustard greens and sunflower seeds), Folic Acid (romaine lettuce, spinach, asparagus, black beans), Vitamin D (more sun exposure, salmon), Vitamin A (carrots, yams, sweet potatoes), spinach, kale), Magnesium (spinach, mustard greens, pumpkin seeds), Phosphorous (almonds, lentils), Zinc (spinach, broccoli, asparagus), Protein (beans, salmon, chicken), Fiber (cauliflower, broccoli, raspberries), Calcium (spinach, mustard greens, kale, oranges) and B12 (salmon).

MyMedSchedule Mobile

Print schedules that are easy to create, read, and update

Keep track of all your medications

Bring your pill schedule to all your medical and dental appointments

Graph results to track progress

Quick and easy data entry

Receive reminders to take your medications by text or email

Refill reminders help you reorder prescriptions before they run out

Works with MedictorPlan.com if your provider has it.

★★★★★

By MedictorPlan.com

Scan the QR code with your smartphone to learn more

Mango Health – Medication Manager

Mango Health makes it fun and easy to manage your medications and supplements in order to reach your health goals. We help you take care of you.

Reliable medication reminders

Pill reminders and alerts when it's time to take your medications

Drug interaction warnings

Notes and reminders

Daily Health Diary

★★★★★

By Mango Health

Scan the QR code with your smartphone to learn more

MedCoach Medication Reminder

Personal medication schedule

Pill reminders and alerts when it's time to take your medications

Log the pills you took

Connect to your pharmacy to refill prescriptions

Create a list of your medications for your doctor or

★★★★★

By GreatCall, Inc.

Scan the QR code with your smartphone to learn more

MediSafe Meds & Pill Reminder

Visual and super easy to handle medication reminder

Synchronizes the family's medicine pillboxes to 1 place

Reminds you to take medication on time, even if your device is asleep

Choose your medication reminder sound to make MediSafe a comfortable addition to your day

Re-sets reminder when you need to retask

★★★★★

By MediSafe Project

Scan the QR code with your smartphone to learn more

VOICE Crisis Alert

A crisis tracking and communicating app

VOICE stands for "Vaso-Occlusive Ischemic Crisis Event" includes a pain tracker, a pain history chart, and the VOICE My Crisis feature, which allows SCD patients or caregivers to communicate pain/ crisis events to pre-authorized contacts of their choice (family members, caregivers, healthcare providers or friends)

★★★★★

All data is kept on the device and will need to be reentered if the user changes devices

By VOICE

Scan the QR code with your smartphone to learn more

Sickle-O-Scope

Only app to track stress and disease symptoms

Users can evaluate their pain and fatigue levels over time

Sharing data with a doctor is possible. Users can - on their own initiative - send data collected by the application to their attending physician

★★★★★

All data is kept on the device and will need to be reentered if the user changes devices

By Sick-O-Scope

Scan the QR code with your smartphone to learn more

SickleWell

Users can manage their disease using alerts, reminders, and education modules

Available on iTunes store

★★★★★

By SickWell

Scan the QR code with your smartphone to learn more

Sickle Cell Anemia

Contains information on sickle cell disease

Causes

Treatments

Prevention

★★★★★

By SickCellAnemia

Scan the QR code with your smartphone to learn more

Sickle Cell Services

Developed by The Sickle Cell Disease Association of America, Inc. (SCDAA) the app provides members of the SCD community access to a database of medical and support services

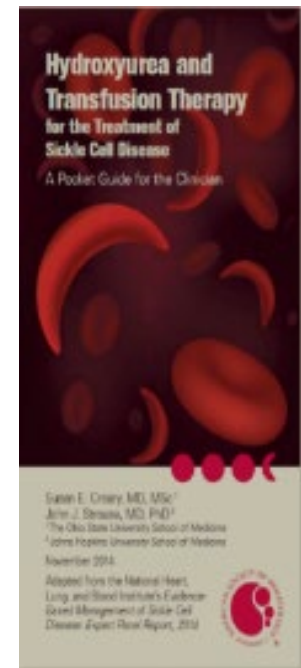
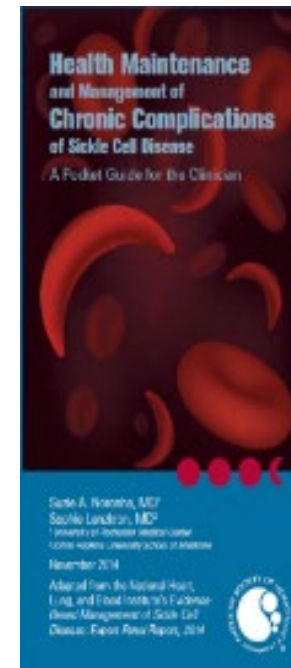
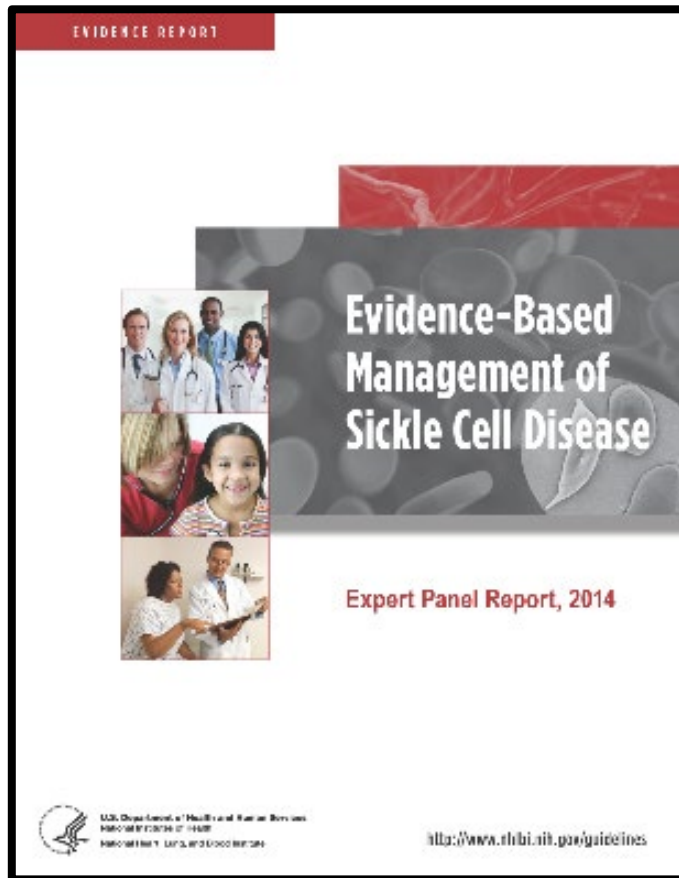
Also provides national news, live message feed from SCDAA, a messaging board and photo submission functionality

★★★★★

By SCDAA

Scan the QR code with your smartphone to learn more

NHLBI Guidelines



STORM TeleECHO Clinic

STORM TeleECHO trains healthcare providers to become more knowledgeable and skilled in the care and management of patients with SCD, with an emphasis on the National Heart, Lung, and Blood Institute's (NHLBI) 2014 evidence-based management guidelines report.

Few providers have the resources to deal with the complex and high-stakes potential complications of SCD. Optimal management requires consultation with highly trained specialists from multiple areas including hematology, nursing, social work, psychology, school staff and others. It is often challenging to receive this type of coordination and multidisciplinary consultation.

STORM TeleECHO
Co-Directors:
Lori Doss, MD, MSc
Lori Doss, MD

Program Specialist
Christine Bennett, MPH, CHES

For more information
Children's Hospital of Pittsburgh
Medical Center
3303 Riverside Ave
Cincinnati, OH 45229
Phone: 513-636-7540
Website: childrens.org
Email: storm@childrens.org

Map of TeleECHO Partners Throughout STORM Network

Indiana
Indiana Hematology and Oncology Center (IHOC)
Indianapolis, IN

Illinois
Children's Hospital of Illinois at OSF Saint Francis Medical Center
Peoria, IL

Michigan
Sickle Cell Disease Foundation of Western Michigan (SCDF-WM)
Detroit, MI

Minnesota
Children's Hospital and Clinics of Minnesota
Minneapolis, MN

Ohio
Cincinnati Children's Hospital Medical Center
Cincinnati, OH

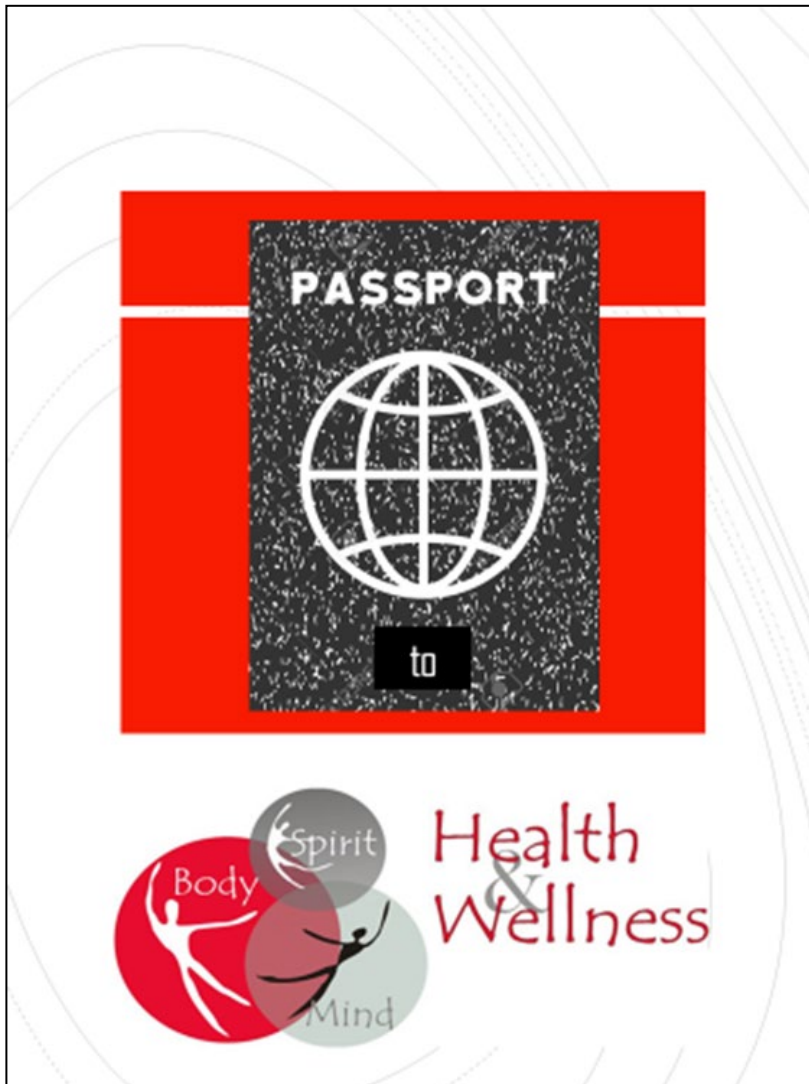
Wisconsin
Medical College of Wisconsin
Children's Hospital of Wisconsin (MCHW)
Milwaukee, WI

STORM
Sickle Cell Disease Research in the Midwest

TeleECHO Clinic for Sickle Cell Disease (SCD)

ECHO
National Center for TeleECHO Education

American Academy of Pediatrics
Improving the lives of all children



Type of sickle cell ____ SS ____ SC ____ Sbeta thal
zero ____ Sbeta thal plus

Other _____

Usual Hemoglobin level _____

Blood Type _____

Allergies:

- Medications
- Hospitalizations
- Transfusion Hx
- Surgical Hx
- Diagnostic Studies
- Medical Appointments



Hertz Nazaire

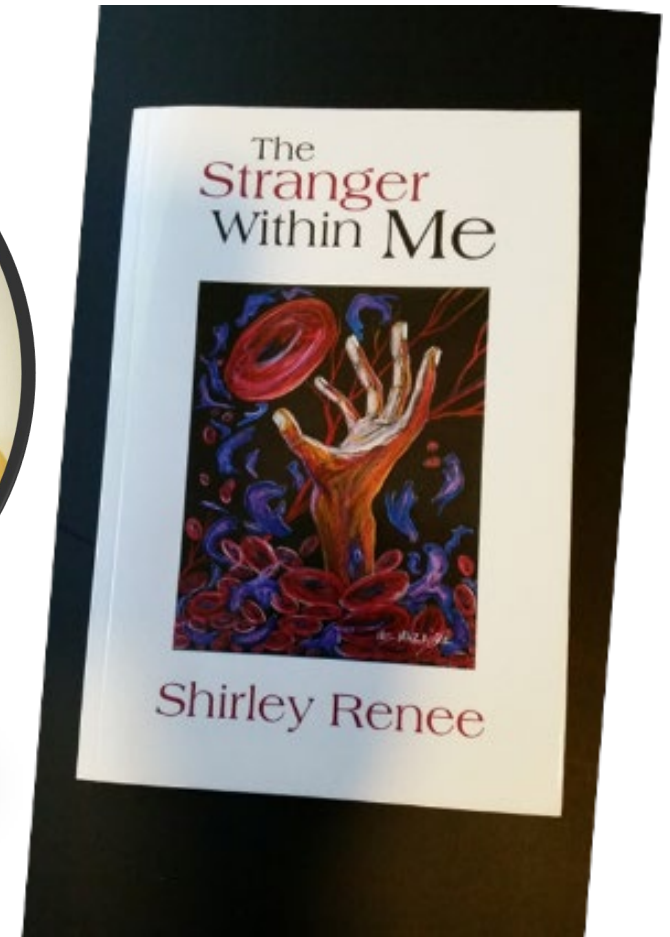


"10 Redefined"

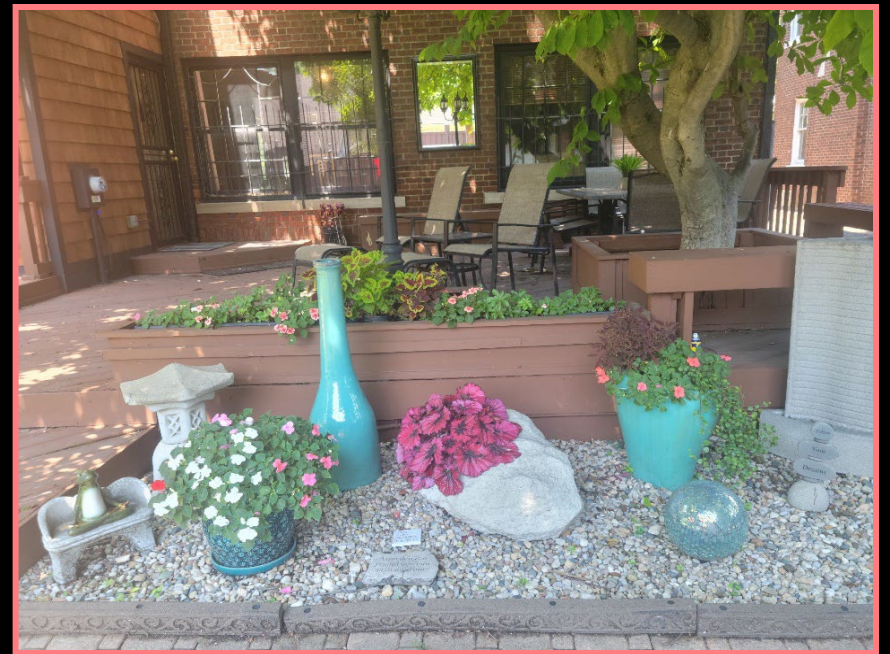


"Hope"

Shirley Miller



**Manager - Adult sickle cell program
Carolinas Healthcare System**



WORLD SICKLE CELL DAY JUNE 19TH

Passion,

The New England Journal of Medicine

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PROPHYLAXIS WITH ORAL PENICILLIN IN CHILDREN WITH SICKLE CELL ANEMIA

A Randomized Trial

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JOHN KELLEHER, M.D., GERALD PRESBURY, M.D., HAROLD ZARKOWSKY, M.D., ELLIOTT VICHINSKY, M.D.,
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FOR THE PROPHYLACTIC PENICILLIN STUDY GROUP



***JUNE
19th
2022***

SHINE THE LIGHT CAMPAIGN

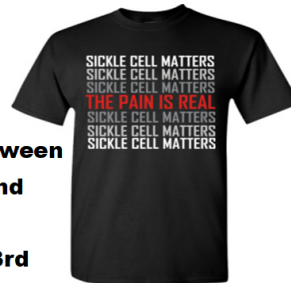
JUNE 19
WORLD
SICKLE
CELL
DAY



June 19th was officially designated as **World Sickle Cell Awareness Day**. The international awareness day is observed annually with the goal to increase public knowledge and understanding of sickle cell disease, and the challenges experienced by patients and their families and caregivers.

This year, please join us in our t-shirt campaign by purchasing a t-shirt. Wear your t-shirt and glow necklace on June 19th as we shine the light on sickle cell and post to your social media page. Don't forget to tag the Community Based Organization in your area!

**Order between
May 2nd
&
May 23rd**



**All t-shirt orders come
with a red glow necklace
and 5 important facts about SCD**



[**TO ORDER YOUR T-SHIRT CLICK HERE**](#)

FOR MORE INFORMATION CONTACT US AT (800) 842-0973



We've come a long way...

THANKS YOU FOR LISTENING

ANY QUESTIONS?

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