Education Visit #1

*** **All** Sickle Cell Patients***

Step 1: Administer Pretest A.

Step 2: Education

- Watch DVD: Education Visit #1 For All Patients
- Handout "So You Have Sickle Cell Disorder"
- Handout "Infection in Sickle Cell Disease"
- Handout "How to Measure a Temperature"
- Handout A Parent's Handbook for Sickle Cell Disease Booklet (birth to 6 years)
- Review "What is Sickle Cell Disease" on p.3 and "What causes Sickle Cell Disease" on p. 8-10 from A Parent's Handbook for Sickle Cell Disease Booklet.
- Give Hematology Division card (names & contact numbers)
- Give local Sickle Cell Foundations Sheet

Step 3: Administer Posttest 01 A.

Step 4: Make 2 copies of test. Give one copy to family and review answers. Place other copy in patient's file for local Sickle Cell Foundation. Place original in Patient's blue Hematology chart.

Step 5: Give patient's return to clinic information.

Initial Visit pretest "A"

Patient's name:

Patient's birth date:

Your name and relationship to patient:

Today's date:

1. Which one of the medications listed below should every child with a sickle cell disease take two times a day? (Unless your sickle cell doctor or nurse tells you differently)
   A. Folic Acid
   B. Penicillin
   C. Vitamins and iron
   D. Desferal

2. When a child with a sickle cell disease has a temperature of _____ you should take them to be seen by a health care provider or the emergency room.
   (Fill in the blank)
   A. 98.6
   B. 99.0
   C. 101.0 or greater
   D. 100.0

3. Sickle cell disease is:
   A. A blood disorder you catch from another person that causes a lot of pain
   B. A red blood cell disorder that you inherit from your parents
   C. A white blood cell disorder that makes someone sick all the time
   D. Does not have any side effects or problems and usually goes away

4. What shape is a sickled cell?
   A. Round, like an apple or circle shaped
   B. Square, like a box or block shaped
   C. Curved, like a banana or comma shaped
   D. Same as any other blood cell

5. How does a child with a sickle cell disease get the disease if both parents only have 1 abnormal hemoglobin trait?
   A. He/she gets only Hemoglobin A genes
   B. By gene therapy
   C. A baby get one abnormal hemoglobin gene from each parent
   D. His/her genes change after birth

6. What is the most common cause of death in CHILDREN who have a sickle cell disease?
   A. Leg ulcers
   B. Anemia
   C. Infection
   D. Pain

7. Which organ in your body acts as a filter to remove broken down red blood cells from the blood stream?
   A. Lungs
   B. Heart
   C. Pancreas
   D. Spleen

8. Anemia is defined as:
   A. Sickle cell disease
   B. Pain in the arms or legs
   C. Difficulty breathing
   D. Low red blood cell count, low hematocrit or hemoglobin

9. The most common complications in children who have a sickle cell disease are:
   A. Infection, pain, anemia, and organ damage
   B. Blindness, hair loss and rash
   C. Constipation, shakiness and difficulty breathing
   D. Fever, vomiting, and stomachache

10. Which immunization(s) is very important in helping to protect a child from getting a pneumococcal infection?
   A. HIV
   B. Prevnar and Pneumovax
   C. Chicken Pox
   D. Hepatitis B

11. Which of the following is MOST likely to cause a child with a sickle cell disease to have a lower than usual blood count?
    A. Spring time
    B. Fever or infection
    C. Traveling
    D. Regular exercising in mild temperatures

12. What do good, healthy red blood cells do in your body?
    A. Carry oxygen to body organs, muscles and tissues
    B. Filter out damaged red blood cells
    C. Remove waste products of red blood cells
    D. Help the body retain fluid

13. Painful swelling of the hands and/or feet in a child with a sickle cell disease is known as:
    A. Pneumonia
    B. chest syndrome
    C. hand and foot syndrome, or dactylitis
    D. splenic sequestration

14. At what earliest age is it possible for a child to first experience a pain crisis?
    A. 1 year
    B. 4-6 months
    C. birth
    D. 3 years

15. Because the kidneys of sickle cell patients do not concentrate urine very well, they are at risk for:
    A. Dehydration
    B. Infection
    C. Stroke
    D. Gallstones

16. Which symptom is more likely in the summer, when a child's level of outside activity increases?
    A. Urinary Tract Infection
    B. Stomach virus
    C. Pneumonia
    D. Sinus infection

17. Which symptom is more likely in the summer, when a child's level of outside activity increases?
    A. Constipation
    B. Splenic sequestration
    C. Dehydration
    D. Pneumonia

18. If a sickle cell patient has stomach pain or swelling, pale color and tiredness, the problem could be:
    A. Pneumonia
    B. Stroke
    C. Dark urine
    D. Splenic sequestration

19. What are the warning signs of gallstones?
    A. Pain in the right side of the abdomen and yellow eyes
    B. Difficulty with urination and fever
    C. Hand and foot pain or swelling
    D. Fast breathing, cough, and chest pain

20. Which complication requires IMMEDIATE medical attention?
    A. Severe headache or dizziness
    B. Runny or stuffy nose
    C. Eyes or skin look yellow
    D. Refuses to take Penicillin

21. Which of the following might be delayed in a child with a sickle cell disease?
    A. teething
    B. saying the first word
    C. toilet training
    D. puberty

22. What is the name of the complication that affects only boys and involves the penis becoming erect, hard and painful?
    A. Stroke
    B. Anemia
    C. Priapism
    D. Splenic sequestration

23. Which changes are likely to cause a sickling episode?
    A. An increase in activity and drinking more fluids
    B. High levels of fetal hemoglobin
    C. Fever, stress, dehydration and a decrease in oxygen
    D. Poor appetite and slow growth

24. A child with a sickle cell disease:
    A. cannot make good grades in school and will not be able to participate in most school activities
    B. can do well in school and participate in most activities with some restrictions
    C. can plan football in school without restrictions
    D. will not do well in classes and should not attend school

25. According to Platt et al. (1994), people with the most severe form of sickle cell disease (Hemoglobin SS Disease) who have NOT had a stroke and who take good care of themselves may have a life expectancy of :
    A. 25 years old
    B. 45 years old or older
    C. 60 years old
    D. The same as someone without sickle cell disease

Reference:

Platt, O.S., Brambilla, D.J., Rosse, W.F., Milner P.F., Castro, Oswaldo, Steinberg, M.H., & Klug, P.P. (1994). Mortality in sickle cell disease: Life expectancy and risk factors for early death. The New England Journal of Medicine, 330(23), 1639-1644.

Initial visit pretest "A"

ANSWER KEY

Name:

Birth date:

Today's date:

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   D. Hepatitis B
   E.

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