

Pediatric Sickle Cell Handbook
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Introduction

Oakland Kaiser Hospital is the regional sickle cell center for the Northern California Kaiser Hospitals, and a California Children's Services (CCS)-approved sickle cell center. We have a full panel of specialists on our sickle cell team including pediatric hematologists (MDs), hematology nurse specialists, social worker, psychologist, physical therapist, nutritionist, child life specialist, and genetics counselors. There is also a full range of pediatric specialists.

If your child was just recently diagnosed with sickle cell, we know this must be a difficult time for your family. We are dedicated to providing the best care for your child. Because the diagnosis affects the whole family, we are also here to provide the best possible care for the other family members. We can accomplish this by helping everyone learn about sickle cell and how to care for the child with sickle cell.

We have written this handbook to help you understand how our sickle cell center works and what services we can provide for you. We want to work with you in caring for your child with sickle cell. Please let us know how our sickle cell center can work best for you and your family.

Oakland Kaiser Permanente Division of Pediatric Hematology 510-752-6592

Staff:

Physicians

Arun A. Rangaswami, MD, Director of Sickle Cell Program
Stacy Month, MD
Laura Campbell, MD
Steven K. Bergstrom, MD

Nurses

Julianne Sherback, RN, BSN, Hematology Nurse Coordinator
Richard McGaffic, RN, Hematology Nurse Coordinator
Laurie Chapman, RN, CPON
Cynthia VanTeyens, RN, BSN
Elizabeth Martin, RN, CPON

Psycho-Social Team

Jeanne Courtney, Licensed Clinical Social Worker
Kim Sherman, Licensed Clinical Social Worker
Carla De Lemos, MA, Certified Child Life Specialist
Amy Nilson, PsyD, Child Psychologist

Clinic Support Staff

Ericka Puentes, Medical Assistant
Susan O'Keith, Receptionist

Managers

James Mitchell, CPNP, Service Manager, Pediatrics
Jean Patrick, RN, Assistant Service Manager, Pediatrics

Hematology Advice Nurse: Call 510-752-6592 Monday through Friday 8:30 to 5:00 p.m.

Emergencies: Call the page operator 510-752-1666 for nights or weekends. Ask to speak with the Pediatric Hematologist on call.

Learning About Sickle Cell Disease

One of the main goals of our sickle cell center is to make sure your whole family is educated about sickle cell — what it is, and how to live with it. This will be a life-long process. As soon as the diagnosis is made, we will start teaching you about sickle cell. We will provide you with numerous excellent booklets about sickle cell. Please let us know what you have already heard about sickle cell, especially if it frightens you. You may have wrong information.

Remember:

- ◆ Sickle Cell Disease is an inherited disease.
- ◆ It affects the red blood cells, which carry oxygen
- ◆ Some common problems are:
 - Painful episodes
 - Anemia (low blood count, getting pale or weak)
 - Infections (especially in the young child)
 - Damage to organs
- ◆ Not every child will have these problems. The disease is variable.
- ◆ Most people with sickle cell can lead active, productive lives.

On your first several visits, we will review information about sickle cell. We want to be available to answer any of your questions. Please let us know if you need more information on a particular topic (i.e. coping with pain, school issues, and new treatments for sickle cell). Our annual sickle cell comprehensive visits include an educational session to refresh your memory as your child grows older.

This handbook will help you learn how to work with us in caring for your child.

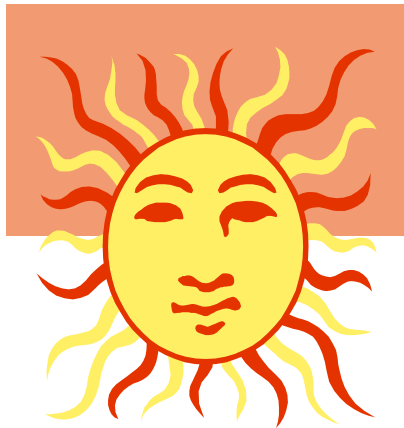
Out-Patient Services — Daytime

Pediatric Sickle Cell Clinic

The Northern California Kaiser Regional Pediatric Sickle Cell Center is located in Oakland in the Piedmont Building, ground floor. Please call 510-752-6592 to schedule or cancel an appointment.

We see patients in the sickle cell clinic for:

- ◆ Routine Sickle Cell appointments
- ◆ Sick visits i.e., pain or high fever (Our infusion area can give blood transfusions, IV fluids, or IV pain medications). If you think your child may need IV fluids for pain, call us as early in the day as possible.
- ◆ Comprehensive Sickle Cell visits (a multi-disciplinary educational session)



All sickle cell patients are assigned to a physician. We will schedule routine sickle cell visits with this doctor. To also help with continuity, the sickle cell nurse is almost always in the clinic for routine as well as sick visits.

We will periodically order routine laboratory tests on your child. These are drawn in the main laboratory down the hall from our clinic, on the ground floor of the hospital tower.

Out-Patient Service — Daytime

General Pediatric Clinic

To help with problems that may come up which are not related to sickle cell disease, we recommend that your child have a regular pediatrician.

Your child can be seen in the general pediatric clinic for:

- Routine check-ups and immunizations
- Minor problems like earaches and sore throats
- Other general childhood problems

Oakland Kaiser's general pediatric outpatient services are located in the Mosswood Building (3505 Broadway). General pediatrics is open for scheduled appointments from 8:30 a.m. to 4:30 p.m., Monday through Friday. The Urgent Care Clinic is open Monday through Friday from 4:30 p.m. to 7 p.m. and on Saturday and Sunday from 10 a.m. to 6 p.m. Call 510-752-1200 to schedule an appointment.

We will work closely with your child's pediatrician and keep them up-to-date on your child's progress.

Sickle Cell Comprehensive Clinic Visits

We believe that your family benefits from having a whole team of experts involved in your child's care. For routine sickle cell check-ups, you will meet with your child's doctor and the sickle cell nurse. In addition, the social worker is almost always available. Once a year we will schedule your child for a comprehensive sickle cell visit at 1:30 p.m. in our clinic. It will give you an opportunity to meet with several other families who have children with sickle cell. In addition, it is a chance to review issues about sickle cell disease and ask any questions. A pediatric hematologist, sickle cell nurse, social worker, nutritionist, physical therapist, and genetics counselor will see your child. For adolescents, an adolescent specialist is also available. These comprehensive clinic visits usually last about 2 hours. Please give us feedback after you attend a comprehensive clinic. We want to make sure we are meeting your family's needs. We encourage **all adults** involved in your child's care to attend.

Out Patient Services — Night-time

Pediatric Urgent Care Appointments

The Urgent Care Clinic is open Monday through Friday from 4:30 p.m. to 7 p.m. and on Saturday and Sunday from 10 a.m. to 6 p.m. Call 510-752-1200 to schedule an appointment.

Emergency Room

If it is after 7:00 p.m., you may need to bring your child to the Emergency Room.

If you think your child needs medical attention in the evening, call the pediatric hematology doctor on-call at 510-752-1666. (Do not call the general pediatric advice nurse, as they may not be totally familiar with special problems related to sickle cell disease.)

The hematology doctors on-call can help you in several ways:

- ◆ They can help you decide if your child must be seen immediately or if you can wait and be seen in our clinic the following day.
- ◆ They can call and talk to the nighttime staff who will be seeing your child. This will help things run more smoothly when you get there.
- ◆ If necessary, they can help your child get admitted to the hospital.

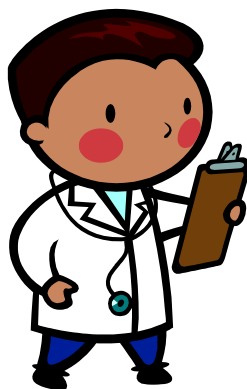


When Should I Call My Doctor? — Urgent Problems

If your child has any of the following symptoms, please call us right away.

- Fever greater than 101.5° F
- Severe chest pain or trouble breathing
- Severe belly pain or swelling
- Severe headache or dizziness
- Painful erection
- Child becoming very pale
- Seizures; child unable to move arm or leg

If any of these problems occur during clinic hours, call 510-752-6592. Let us know if you think it is an emergency. If it is an evening or weekend, call the page operator at 510-752-1666 and ask to speak to the pediatric hematologist on call. We will give you instructions on how to get medical attention right away.



When Should I Call My Doctor? — Routine Problems

If your child has any of the following symptoms, please call the hematology advice nurse during the day at 510-752-6592.

- Vomiting more than once; diarrhea more than once
- Jaundice (eyes or skin look yellow)
- Mild pain anywhere on the body
- Cough, runny nose
- Refusing to eat or drink
- Child not acting right, decreased activity

These are generally not emergencies. Often we can give you telephone advice and you may not need to bring your child in.

When Your Child Is Hospitalized

We try very hard to keep your child healthy and out of the hospital. However, children with sickle cell sometimes need to be hospitalized. We know this can be a scary or stressful time for families.

The 10th floor of the Oakland Kaiser Hospital is devoted to pediatric patients. All the doctors and nurses there are pediatric specialists and are familiar with caring for sickle cell patients. Occasionally, some of our older adolescents may be admitted to the 9th floor.

Some of the common reasons that patients with sickle cell disease are admitted to the hospital are:

- ◆ Very high fever
- ◆ Severe pain (not responding to oral medications or treatment in the clinic)
- ◆ Very severe anemia (children need to be monitored carefully and receive blood)
- ◆ Pneumonia (this is serious in children with sickle cell, so we always admit them)
- ◆ Greatly enlarged spleen (this can be life-threatening, so children must be monitored closely)
- ◆ Operations such as the removal of the gall-bladder

A team of pediatricians and pediatric nurses will care for your child with the guidance of your child's sickle cell doctor. A pediatric hematologist will be seeing your child at least once or twice a day. The sickle cell nurse, social worker, child life specialist and psychologist will also continue to see your child as needed. We encourage you to stay with your child as much as possible. If you can't be there all the time, leave us your phone number, so we can keep you up-to-date on your child's condition and to make sure you understand everything that is going on.

When your child leaves the hospital, we will give him or her a follow-up appointment in our clinic to ensure continuity.

Important Medicines for Children with Sickle Cell

PENICILLIN

1. Penicillin is an antibiotic. It is given two times a day. It can save your child's life by helping to prevent serious infection.

| Age | Dose |
|---------------|---|
| Birth - 3 yrs | 125 mg (1 teaspoon) twice a day |
| Over 3 years | 250 mg (1 tsp. or 1 tablet) twice a day |

*** Here are some tips ***

- ◆ If your child is taking liquid medication, we will prescribe 3-4 bottles at one time. The pharmacist will mix the first bottle. The other bottles will have dry powder and you will be instructed how to add water. Each bottle is good for 2 weeks if **refrigerated**.
- ◆ The pills can be crushed and mixed with food, formula, or juices.
- ◆ Have your child take penicillin every day.
- ◆ **Don't run out of medication.** We will give you refills for 1 year. Call the sickle cell nurse if you need more refills.
- ◆ If your child needs another antibiotic (i.e. for an ear infection) you can stop the penicillin while he/she is on the other antibiotic.

FOLATE

Folate or Folic Acid is an important vitamin for making healthy "new" red blood cells. It is given once a day. It only comes in tablet form, not in liquid.

*** Here are some tips ***

- ◆ When your child is very young you should crush up the tablet and mix it with a small amount of food, formula, or juice.
- ◆ If you miss a few days occasionally, don't panic, but missing many days or weeks at a time can be a problem.
- ◆ Be sure you do not run out of medication. We will give you refills for 1 year. Call the sickle cell nurse if you need more refills.

Important Medicines for Children with Sickle Cell - continued

PAIN MEDICATIONS

You need to anticipate pain in your child, so you will be prepared for the first time it happens.

*** You should have at home ***

- ◆ **Tylenol** - for mild pain
Know your child's correct dose. Ask us if you are unsure.
- ◆ **Tylenol with Codeine or Motrin** - for more severe pain
Your doctor will give you a prescription for these medications. Ask for it if you don't have one.
- ◆ **Percocet** - for patients who have a history of severe pain.
- ◆◆ **Don't run out of the Medications you need.** Having enough at home can save you a trip to the hospital in the middle of the night.



Dealing with Pain

An important goal of our sickle cell center is to teach parents about pain in children who have sickle disease, so they can provide better home care for them. A child with sickle cell can have pain as early as 6 months of age. Some children, however, may not experience pain until they are school age. Every child is different. Children are sometimes too young, too sick or too afraid to say how much pain they are in. There is no machine or lab test that can quantify the amount of pain someone is feeling.

We feel that parents play an important role in pain management because they are experts on their child's behavior and reactions. Parents also know best how to comfort their child. We give all our families with sickle cell a booklet devoted solely to pain management, and the specific role of the clinic staff, the parent, and the patient. Ask for it if you do not have one.

Here are a few tips:

- ◆ Start with Tylenol. If this isn't strong enough, your doctor can prescribe Tylenol with codeine. Alternate it with Motrin.
- ◆ Heat is helpful, especially moist heat (Try heating pads, hot water bottles, warm moist towels or hot baths).
- ◆ Your child should drink lots of fluids.
- ◆ Massage is helpful.
- ◆ Try distracting your child with music, TV, toys.
- ◆ Encourage your child to rest or play quietly.

Psychosocial Services

The pediatric sickle cell center at Kaiser Permanente is here not just to take care of the medical needs of the child with sickle cell disease. We are committed to taking care of the emotional and psychological problems of the whole family. We know that having a child with a chronic disease can sometimes cause stresses on the family. The next few pages are examples of how we can help.



Psychologist

There is a child psychologist in our division, available to help in the areas of emotional and behavioral adjustment of children and families dealing with chronic illness. We are aware that having a child with sickle cell disease can sometimes be stressful. The psychologist is trained to help families through difficult times. Consulting with a psychologist is not a sign of mental illness. The psychologist may also be able to teach you and your child about pain control, and help in ensuring a positive approach toward your child's school by facilitating long-range goals for their educational needs.

Social Worker

The hematology social worker meets with each family in order to complete a personalized assessment. The assessment includes a discussion of your child's medical condition, availability of family support, coping skills and identification of any services, which may be required. Services may include referrals to community resources and agencies such as Vocational Rehabilitation. If a family is experiencing financial difficulties, referrals are made to financial assistance programs such as California Children Services (CCS), Supplemental Security Income (SSI), and the Women, Infants, and Children (WIC) program.

Facilitating appropriate use of health care services with our Medical Center is also an integral part of the social worker's focus. If your child is hospitalized, we play an important role in the development of the discharge plan and continuing care planning (maintaining consistent clinic follow-up).

An ongoing family support group is available for parents to come together and share issues, concerns and experiences regarding coping with your child's medical condition. Groups are often a great environment in which to interact and become familiar with other parents who are experiencing similar situations. Our "Buddy System" program, in which parents are individually matched with another parent(s), has also proven to be a beneficial coping tool.

As part of the Hematology team, the primary role of the Social Worker is to be an advocate, for Sickle Cell patients, and their families, and to ensure that our families receive the best possible benefits and services.

School Issues

The team's sickle cell social worker and psychologist are readily available to help parents with their child's school program. We will give you a sickle cell parent/teacher guide to aid in good communication. Sickle cell has been associated with learning problems in some children. Your child's school must provide the special help your child may need. Parents may request testing to determine if their child needs special help. If your child does need Special Education, an Individualized Education Plan (IEP) will be developed. Parents can assist in writing the IEP and are also entitled to participate in the IEP meeting with school staff. This will give the parent an opportunity to provide valuable information regarding their child's academic needs. A parent may also request, in writing, a meeting with school staff to discuss the IEP and any desired changes in the IEP evaluation. The goals and objectives of the IEP include recommendations to enhance the child's academic success. Our Pediatric Hematology staff feels very strongly that success in school enables the sickle cell patient to become not just someone who has an illness, but one who has developed and learned and has been given the opportunity to be a truly successful adult. The expectation of parents, teachers, and health care providers of staying in school says to the child, "you have a future."



Sickle Cell Disease Resource List

African American Organizations

| | |
|--------------------------------------|--------------|
| Omega Boys Club | 510-638-2857 |
| Contact: Afrige Quamina | 510-832-0915 |
| Sickle Cell Community Health Network | |
| 610 - 16 th St. | |
| Suite 400 | |
| Oakland, CA 94612 | 510-628-0610 |

Counseling Services

| | |
|---|--------------|
| Center for Family Counseling | 510-562-3731 |
| Kaiser Psychiatry Department | 510-752-1075 |
| Kaiser Pediatric Hematology Division | 510-752-6592 |
| West Coast Children's Center (Accepts Medi-Cal/Sliding scale) | |
| 545 Ashbury Avenue | |
| El Cerrito, CA 94530 | 510-527-7249 |

Counseling Centers

JFKU has three counseling centers that all provide sliding scale counseling to residents of their communities. *GSPC Community Counseling Centers* in **Pleasant Hill** (925-798-9240) and **Sunnyvale** (408-524-4900) provide counseling to the *Acalanes* and *Cupertino* school districts respectively. The *GSHS Center for Holistic Counseling* in **Oakland** (510-444-3344) offers a mind-body approach to counseling.

Crisis Counseling

Crisis Support Services of Alameda County

P.O. Box 9102

Berkeley, CA 94709

Confidential 24-hour telephone crisis, counseling and referral service.

Cost: free to call crisis line; sliding scale for therapy groups.

| | |
|----------------------|--------------|
| Contact: Crisis Line | 510-848-1515 |
| Business Office | 510-889-1104 |

| | |
|-------------------------------|--------------|
| Contra Costa Crisis Center | 800-833-2900 |
| Solano Country Crisis Hotline | 707-428-1131 |

Educational Materials

Kaiser Health Education Libraries

| | |
|---------------|--------------|
| Oakland | 510-752-6204 |
| San Francisco | 415-833-3450 |
| Stockton | 209-476-3299 |
| Santa Clara | 408-236-5684 |
| Richmond | 510-307-2210 |
| Vallejo | 707-651-2692 |

Videos to watch in clinic:

"Invisible Illness: Living with Sickle Cell Anemia"

"Where's Herbie?"

"Taking Care of Your Own"

Pamphlets available from clinic:

"Fact Sheet on Sickle Beta Thalassemia Disease"

"Sickle Cell Anemia, What is it?"

"Parent/Teacher Guide"

"Parent's Handbook for Sickle Cell Disease" Part I (Birth to 6 yrs), Part II (6 to 18 yrs)

Financial Assistance

For: CalWorks
Food stamps
General Assistance
Medi-Cal

Apply by county:

| | |
|--------------|--------------|
| Alameda | 510-383-8523 |
| Contra Costa | 925-313-7987 |
| Marin | 415-473-3400 |
| Napa | 707-253-4511 |
| Solano | 800-400-6001 |
| Sonoma | 800-331-2278 |

Financial Assistance, cont'd

Women, Infants and Children (WIC)

How to apply for WIC services: Call 510-595-6400 to make an appointment. At your appointment, WIC staff will check to see if you and your family qualify. The staff will tell you what paperwork you will need to apply.

If you live elsewhere in California, please call the toll-free number below for more information and to find the WIC office location closest to your home. Call Toll Free 1-888-WIC-WORKS (1-888-942-9675).

Social Security (SSI) 800-772-1213

California Children's Services (CCS)

By County:

- Alameda 510-208-5970
- Contra Costa 925-313-6100
- Napa 707-253-4391
- San Francisco 415-575-5700
- San Joaquin 209-953-3600
- Santa Clara 408-793-6200
- Solano 707-784-8650
- Stanislaus 209-558-7515

Genetic Counseling

Kaiser-Oakland Genetic Counseling 510-752-6298

Kaiser San Francisco Genetic Counseling 415-833-2998

Sickle Cell Counseling Center (Genetic Disease branch of Department of Health Services) - counseling free of charge 866-954-2229

Insurance

Alameda Alliance Health Plan
Member Services 510-747-4567

Health Care Options 800-430-4263

Genetically Handicapped Person Program
(GHPP) (over 21 years of age) 800-639-0597

Legal Services

Bay Area Legal Aid 800-551-5554 www.baylegal.org

Provides free legal services to low income residents of 7 Bay Area Counties

East Bay Community Law Center 510-548-4040 www.ebclc.org

Community Educational Workshops representation intervention and public housing matters

Eviction Defense Center 510-452-4541

Housing Rights, Inc 510-548-8776 www.housingrights.org

NAACP Legal Defense Fund 800-221-7822 www.naacpldf.org

Recreation

Sickle Cell Camp 510-752-6592

Kids First www.kidsfirst.org

Respite Care

Bananas (North Alameda County Only) 510-658-6177

Child Care Coordinating Council (South Alameda County) 510-582-2189

Sickle Cell Support Groups

Sickle Cell Community Health Network

610 - 16th St., Suite 400
Oakland, CA 94612

510-628-0610

The Community Advisory Committee meets the first Thursday of each month at Children's Hospital and Research Center at Oakland. Everyone who cares about sickle cell disease is welcome to attend. Call Eileen Murray for details:

510-428-3452

Transportation

| | |
|---|--------------|
| A.C. Transit | 510-891-4706 |
| (Discount passes are available to certified disabled individuals) | |
| Oakland | 510-238-3036 |
| Berkeley (Mon-Thurs, 8 to 12 Noon) | 510-981-7269 |

Vocational Rehabilitation

California Department of Vocational Rehabilitation

| | |
|---|--------------|
| Berkeley | 510-883-6000 |
| San Francisco | 415-904-7100 |
| Oakland | 510-622-2764 |
| Vallejo/Fairfield | 707-648-4010 |
| Mt. Diablo Delta District (Antioch, Richmond) | 925-602-3953 |
| Workforce Investment Board | 510-670-5700 |
| Job Corps | 800-733-JOBS |
| Job Star | 510-768-4473 |

Sickle Cell Care Websites

The Sickle Cell Information Center

The Georgia Comprehensive Sickle Cell Center at Grady Health System
Emory School of Medicine, Department of Pediatrics, Atlanta, Georgia

www.scinfo.org

Agency for Health Care Policy and Research

<http://www.ahcpr.gov/>

Children's Hospital Oakland - Thalassemia Center

<http://www.thalssemia.com>

Joint Center for Sickle Cell and Thalassemic Disorders

Partners in Health Care, Inc.

<http://sickle.bwh.harvard.edu>

National Heart, Lung and Blood Institute <http://www.nhlbi.nih.gov/>

Sickle Cell Advocates for Research and Empowerment

<http://www.defiers.com>

University of Rochester Medical Center

<http://www.urmc.edu/medicine/genetics/>

Sickle Cell Disease Association of America, Inc.

<http://www.sicklecelldisease.org/>

Sample Letters

Our staff will be happy to provide you with letters to your child's teachers to help your child get appropriate and fair treatment at school. We also can give you a letter to carry with you when you are traveling in case you need to seek medical help at a place where people are unfamiliar with the care of children with sickle cell. Samples of these letters are shown on the next few pages. If your family needs additional letters for individual problems, please let us know.

Sample School Letter

Date: _____

Patient _____

MR # _____

DOB: _____

Dear Educator:

The above-named patient is a _____-year-old followed at Oakland Kaiser Hospital for sickle cell disease. He/she is capable of normal school performance, but has some special needs. We recommend:

1. He/she should have unlimited access to the rest room.
2. He/she should have unlimited use of the water fountain, or be allowed to bring his/her individual water bottle into the classroom.
3. He/she must be allowed to take oral medication (i.e., Tylenol, Motrin, Tylenol with Codeine) at school. This will enable the child to come back to school sooner and have fewer absences.

We hope the enclosed pamphlets will contribute to a successful and productive school year. Please feel free to contact our pediatric hematology department at Kaiser Permanente in Oakland at 510-752-6592.

Sincerely,

Pediatric Hematology staff

Sample Letter to Physical Education Teacher

Date: _____

Patient _____

MR # _____

DOB: _____

Dear Educator:

The above-named patient is a _____-year-old followed at Oakland Kaiser Hospital for sickle cell disease. In general, he/she is capable of normal participation in physical education. However, certain strenuous activities should always be avoided:

- Continuous exercise longer than 15 minutes,
- Continuous running longer than 15 minutes,
- Contact sports, i.e., football, wrestling, etc.
- Swimming in cold water.

Sickle cell patients may at times experience pains in the limbs, shortness of breath, or other symptoms with strenuous physical activity. He/she should be excused from such activities at these times, but alternatives should be sought which will allow as much participation as possible in group activities, without forcing the child beyond these temporary limitations.

He/she should be given the opportunity to drink freely to replenish fluids (we recommend using an individual water bottle) and should have unrestricted access to the restroom.

If you have any questions or concerns, please feel free to contact our pediatric hematology department at Kaiser Oakland at (510) 752-6592.

Sincerely,

Pediatric Hematology staff

Sample Individual Education Plan (IEP) Letter

Date: _____

School: _____

Address: _____

City/State/Zip: _____

Re: Patient _____

MR # _____

DOB: _____

Dear Principal:

My daughter/son attends your school. She/he has sickle cell disease. Her/his doctors have informed me that studies over the past ten years suggest that learning problems are more common in children with sickle cell disease.

I am concerned about my child and I am requesting testing to determine if she/he has any special educational needs. I would then like to have a conference to discuss your findings and my child's IEP (Individual Education Plan).

Thank you for your prompt attention to this matter.

Sincerely,

Signature of Parent/Guardian

Sample IEP Follow-Up Letter

Date: _____

School: _____

Address: _____

City/State/Zip: _____

Re: Patient _____

MR # _____

DOB: _____

Dear Principal:

My daughter/son attends your school and has sickle cell disease. Recently we have had tests done to determine if she/he has special educational needs. I would like to schedule a meeting with you to discuss the results of the tests and my child's Individual Education Plan (IEP).

Thank you for your prompt attention to this matter.

Sincerely,

Signature of Parent/Guardian

Sample Travel Letter

Date: _____

Patient _____

MR # _____

DOB: _____

Dear Health Care Provider:

The above-named child is a _____-year-old followed at Oakland Kaiser Hospital for sickle cell disease.

Date of last visit: _____

Recent Labs: _____

Hgb: _____ Hct: _____ Retic: _____ Bili: _____

Immunizations Current?: Yes [] No []

Routine Medication:

[] Pen VK 125mg 5cc BID

[] Pen VK 250mg 5cc BID

[] Pen VK 250mg tab BID

[] Folate 1mg daily

Other Medication: _____

Allergies: _____

Problems: _____

The major risks for patients with sickle cell disease include infection and vaso-occlusive crisis (VOC). Infections to which children with sickle cell disease are particularly susceptible include pneumococcus, H.flu, E.Coli, salmonella, and mycoplasma.

These children are functionally asplenic and any fever of 101° or greater warrants a thorough evaluation. In general, for the child under one year of age a complete septic work up is indicated. Admission to the hospital for a 72-hour course of antibiotics to rule out bacterial sepsis is indicated in the child under three years of age with a temperature of >101.5°, or if the child is over three years with a temperature of 103°. A broad spectrum antibiotic such as Cefotaxime or Cefuroxime (150mg/kg/day) provides good coverage. In selected cases, a child could be treated as an outpatient with daily IM/IV ceftriaxone. If clinical symptoms or chest x-ray suggests pneumonia, coverage for mycoplasma is useful as well.

Vaso-occlusive crisis (VOC) usually develops in the setting of stress, dehydration, infection, or high altitude. Many VOC can be managed with vigorous hydration and analgesia. All patients with an onset of pulmonary symptoms, headache, abdominal pain, back pain, or bone pain should be evaluated and admitted for hydration if unable to take twice-maintenance p.o. and/or if pain can not be managed by p.o. tylenol/codeine, or by one to two doses of ketorolac or morphine. If there is suggestion of acute chest syndrome (VOC in lungs), or if a child does not seem to improve with standard management of VOC, please contact us for consultation unless you are at a tertiary care center.

Please call if you have any questions. We can be reached between 9:00am-5:00 pm Monday through Friday at 510-752-6592 and after 5:00pm and on weekends at 510-752-1666. Thank you for sharing in the care of this patient.

Sincerely,

Pediatric Hematology Department

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