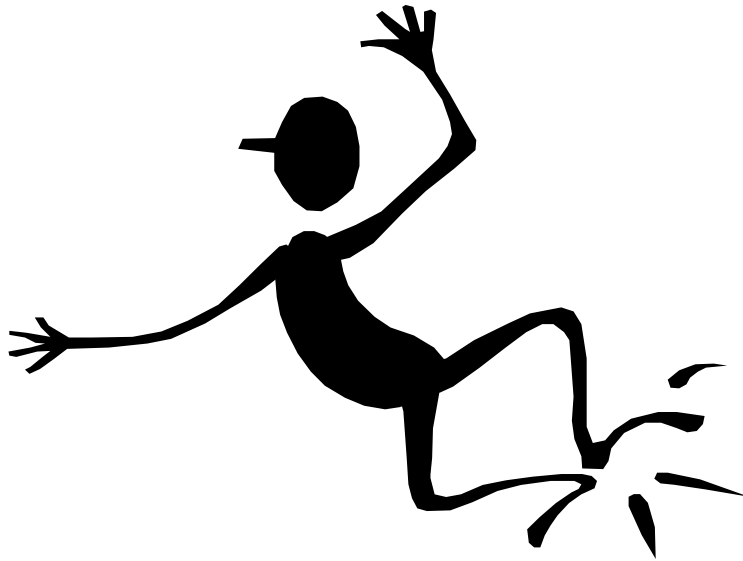


POST-HEART TRANSPLANT TEACHING

CONGRATULATIONS ON YOUR TRANSPLANT



SUTTER TRANSPLANT SERVICES

5151 F STREET

SACRAMENTO, CA 95819

PH# (916) 733-8133

FAX # (916) 733-1967

I. ANATOMY AND PHYSIOLOGY

The heart is a muscular, cone-shaped organ that is a two-sided pump, about the size of a fist.

The right side of the heart receives oxygen poor blood from the body, it then flows into the right ventricle and pumped through the pulmonary artery into the lungs where the blood is oxygenated. The oxygenated blood is then pumped through the pulmonary veins to the left side of the heart, where is pumped out through the body. The heart receives its blood supply from the coronary arteries that envelop the heart.

The heart has a specialized system that conducts electrical impulses allowing the heart to contract. The pacemaker of the heart is located in the right atrium of the heart. Because the nerve connections to the heart are severed during the transplant surgery and are not reconnected to the transplanted heart, there is no nerve stimulation of the heart. The heart rate and response to stressors is therefore regulated through circulating hormones and will therefore be slightly slower than the response if the nerve connections are still intact. The actual severing of the nerves is called heart denervation. The heart transplant recipient should, therefore, warm up before and cool down after any vigorous activity. Another effect of denervation of the heart is that you will not feel chest pain, because of this we will require that you undergo a heart catheterization every other year to check for coronary artery disease. Finally, because of the severed nerve connections your resting heart rate will be slightly elevated >90.

II. TRANSPLANT DIARY

All transplant recipients are requested to keep a transplant diary. The type of diary is entirely up to you. Some of the suggestions are: binders, computer files, notebooks, etc.

A. What to record daily in your transplant diary:

1. Weight – first thing in the morning after urination
2. Blood pressure and heart rate - first thing in the morning and in the evening before dinner
3. Blood sugar (if applicable) – as directed by your transplant coordinator
4. Temperature – first thing in the morning
5. Medication changes – any changes to your medication regimen

III. MEDICATIONS

This section is intended to be a general guide of typical transplant medications, their functions, dosages, precautions, and side effects. This information does not cover all aspects of each medication and is not intended as medical advice for individual problems. The purpose is simply to give you a general overview of the medications you will be taking. Always follow the instructions of your transplant team. You will need to take immunosuppressive medication as long as you have your transplanted heart. The medications, dosages and side-effects will be different for each transplant patient. Due to the side effects of these medications, you will be required to take additional medication to decrease the side effects. **Please, keep an extra 2 week supply of medications on hand at all times!**

A. Immunosuppressive Medications:

1. PREDNISON: acts to suppress the body's immune response to the transplanted heart.

Side effects:

- Changes in your physical appearance e.g.; round cheeks, increased body and facial hair growth, acne
- Increased appetite
- Increase weight gain
- Susceptibility to infection
- Excess stomach acid and increased risk to developing ulcers
- Increased skin bruising/injuring
- Increased sun sensitivity
- Slower wound healing
- Increased risk of osteoporosis
- Muscle weakness
- Steroid induced diabetes
- Cataract formation
- Mood swings

Dosing:

- Prednisone is ordered in 5 mg tablets, therefore to take 25mg you would take 5 5mg tablets, to make 22.5 mg you would take 4, 5mg tablets and ½ of a 5 mg tablet
- Please take you prednisone in the morning as this best corresponds to your natural prednisone production
- Do not take prednisone on an empty stomach as this can cause severe stomach upset

III. MEDICATIONS (CONT'D)

A. Immunosuppressive Medications: (cont'd)

2. NEORAL/ GENGRAF (cyclosporine): acts to suppress the body's immune response to the transplanted heart

Side effects:

- Kidney damage
- Liver damage
- Increase hair/nail growth
- High blood pressure
- Mild tremors, especially in the hands
- Increased risk of infection
- Headache
- Swollen gums
- Increase risk of developing cancer
- Sleep disturbances

Dosing:

- Neoral comes in 100 mg and 25 mg capsules
- Neoral must be taken as close to 12 hours apart as possible
- When you are scheduled for a cyclosporine level you must take your evening dose the night before 11 ½ hours before you are scheduled to have your blood drawn and do not take your morning dose of Neoral until you have had your blood drawn

3. PROGRAF (Tacrolimus, FK506): acts to suppress the body's immune response to the transplanted heart

Side effects:

- Headaches
- Nausea
- Diarrhea
- Tremors
- High blood sugar
- Kidney damage
- Hair loss
- Sleep disturbances
- Numbness/tingling of hands and/or feet

Dosing:

- Prograf comes in 5mg and 1mg capsules
- Prograf must be taken as close to 12 hours apart as possible
- When you are scheduled for a tacrilomus level you must take your evening dose the night before 11 ½ hours before you are scheduled to have your blood drawn and do not take your morning dose of Prograf until you have had your blood drawn

4. CELLCEPT/MYFORTIC: acts to suppress the body's immune response to the transplanted heart

Side effects:

- Nausea/vomiting
- Diarrhea
- Increased risk of infection
- Blood abnormalities

Dosing:

- Cellcept comes in 250 mg and 500 mg capsules
- Myfortic comes in 180 mg and 360 mg capsules
- Both must be taken as close to 12 hours apart as possible
- If persistent diarrhea or vomiting occur with this medication, please contact your transplant coordinator

B. Other medications:

1. Antifungals (Nystatin) to help prevent fungal infections e.g. thrush
2. Antivirals (Acyclovir, Ganciclovir) to help prevent specific viral infections e.g. CMV
3. Antibiotic (Septra) to prevent specific infections e.g. pneumocystis pneumonia
4. Antihypertensives to lower blood pressure
5. Diuretics (Lasix) to help rid the body of excess fluid
6. Antacid (Maalox) and Pepcid to help protect the stomach from irritation and ulcer development
7. Multivitamin
8. Vitamin D and Calcium to protect bones
9. Enteric Coated Aspirin
10. Cholesterol lowering medication

III. MEDICATIONS (CONT'D)

C. Do's and don'ts of your medication regimen:

1. Do not double up after a missed dose, call your transplant coordinator for instruction
2. Do not use any over-the-counter medications, or drugs prescribed by physicians other than the transplant physicians without contacting your transplant coordinator first
3. Notify transplant team if persistent nausea, vomiting or diarrhea occur, this can change the absorption of your medications
4. Do not store medications in places that may be subjected to extreme temperatures, i.e. cars, direct sunlight, refrigerator, etc.

5. Do not adjust your medications without direction from your transplant coordinator, or transplant physician
6. Establish a method to help you take your medications in a timely manner
7. If a medication is scheduled for twice daily it should be 12 hours apart, three times daily should be 8 hours apart, four times daily should be 6 hours apart, and for once daily medications find a time in the morning when you know you will be able to take them consistently
8. When taking your medications you have a half hour leeway from the time you are scheduled to take them
9. Do not ever stop a medication without the direction of your transplant team
10. If a physician other than a transplant physician orders a new medication, or changes an existing medication, please contact a transplant coordinator prior to making any changes or adding new medications

IV. BLOOD PRESSURE

Your blood pressure (B/P) consists of 2 numbers; a top number called the systolic and a bottom number called the diastolic.

A. Hypertension (high blood pressure):

Can cause damage to the heart and other organs over a period of time and needs to be treated.

Symptoms of high blood pressure are:

1. Feeling of flushing
2. Headache
3. Ringing in your ears

B. Hypotension (low blood pressure):

Can be caused by dehydration or a sudden change in your position.

Symptoms of low blood pressure are:

1. Weakness
2. Fatigue
3. Dizziness

C. **Blood pressure reporting:**

1. Check and record your blood pressure first thing in the morning before you take any of your morning medications
2. Normal blood pressure ranges from 90/60 to 140/90
3. Report any blood pressures >170/110 or <100/60
4. Prevent rapid changes in your blood pressure by changing positions gradually

V. **ACUTE REJECTION:**

The immune system allows the body to distinguish between self and foreign. An immune response occurs when the body recognizes the presence of a foreign body. Your immune system will always recognize your transplanted heart as foreign, that is why you take the above mentioned immunosuppressive drugs. Rejection can occur at differing times after your transplant; however it occurs most often within the first year after transplant. This is why you are scheduled for frequent biopsies within the first year after transplant, since a biopsy of your transplanted heart is the only true way to determine whether a rejection is occurring. This type of rejection is termed an acute rejection. Note: rejections most often occur when there isn't enough immunosuppressive medication in your blood that is why it is essential that you take your immunosuppressive medication as prescribed by your transplant physician, every single day.

A. **Signs and Symptoms of Acute rejection:**

1. Rapid weight gain; 2# per day or 4# in a week
2. "Flu-like" symptoms; e.g. chills, aches, fatigue, head aches, dizziness, nausea, etc.
3. Change in pulse rate or heart rhythm
4. Shortness of breath
5. Sudden changes in blood pressure
6. Signs and symptoms of congestive heart failure
7. General feeling of "just not feeling right"

B. **Reporting of Symptoms:**

1. Report symptoms immediately to your transplant coordinator
2. Be prepared for a possible hospitalization which could include an echocardiogram, urgent biopsy, and/or increase in immunosuppressive medication, and/or IV immunosuppressive medications
3. REMEMBER: most acute rejection episodes can be reversed if symptoms are reported promptly and treatment is started immediately

VI. CHRONIC REJECTION:

Another way for the immune system to reject your transplanted heart is through what is called chronic rejection. Chronic rejection is coronary artery disease. Because of this chronic rejection you will be scheduled for an angiogram (an x-ray of the arteries of your heart) every other year starting with year 1. On the years when an angiogram is not done, you will be scheduled for a stress echocardiogram. Your first annual will consist of a biopsy, an angiogram, a stress echocardiogram, an EKG, and routine lab work and is scheduled near to your first year anniversary of your transplant. Your second annual will consist of a biopsy, a stress echocardiogram, an EKG, and routine lab work. If however coronary artery disease is noted, you will undergo an angiogram with every annual. Remember, because of the denervation of your heart, you may not experience chest pain, and the angiograms and stress echocardiograms will be the only way to monitor for coronary artery disease. The best way to minimize this type of rejection is through diet, exercise, and taking your immunosuppressive drugs as prescribed.

VII. ENDOMYOCARDIAL BIOPSY:

After you have been transplanted you will undergo frequent biopsies. A biopsy is performed by inserting a catheter into a vein in your neck or your groin. A biopptome is then inserted through this catheter and a snippet of tissue is removed. The tissue is thinly sliced, and placed on a microscope slide. The pathologist then looks at the slide and determines the level of rejection. Biopsies are graded from a 0 (no rejection) to a 3R (most rejection possible). Most acute rejections can be successfully treated if they are diagnosed promptly. Most transplant recipients will have 1 or more episodes of rejection that will need to be treated within the first year after transplant. The severity of the rejection will determine the type of treatment necessary.

A. Preparation for biopsies:

1. Nothing to eat or drink for 12 hours prior to the biopsy (OK to take evening dose of medications with sips of water)
2. Do not take your morning dose of medications , but bring them with you to the hospital
3. Arrive at the hospital no later than 6:15 a.m. to register
4. Lab work will be drawn upon arrival
5. It is important to take your evening dose of Neoral at 7:00 p.m. the evening before a scheduled biopsy to obtain an accurate level
6. Recovery time after a biopsy is typically 2-3 hours for a routine biopsy, 6-8 hours for an angiogram
7. If you are having an angiogram, you will not be able to drive yourself back home

B. Frequency of biopsies and clinic appointments:

1. Biopsies will be performed once a week for the first month; the first biopsy will be performed before discharge from the hospital. If the first 4 biopsies are acceptable then the following biopsies will be at increasing intervals, i.e. every 2 weeks, then every 3 weeks, then once a month, etc.
2. REMEMBER: if you have a rejection episode, you will be biopsied more frequently
2. Every biopsy will be followed by a clinic appointment. Clinics are every Wednesday starting at 1:00 pm.

C. Biopsy FYI's:

1. For those of you who live farther than 1½ hours away from Sutter Memorial, we will do our best to schedule your biopsy and your clinic appointments on the same day, please understand that this can not be guaranteed
3. Biopsies are scheduled by the transplant support representative (TSR) in the transplant office, and are tracked by the transplant department. If an emergency arises and you will not be able to keep your biopsy appointment, please notify the transplant department as well as your transplant cardiologist office. We will try to accommodate any special requests, but please be aware that this is not always possible
4. Please bring your transplant diary with you to every clinic for review with your transplant team

VIII. INFECTION:

Infections are a constant risk to a transplant recipient. The immunosuppressive medication will decrease your body's natural ability to fight off infection. What this means is that a cold or the flu can more easily turn into a bronchitis or a pneumonia more quickly in a transplant recipient.

A. Prevention of Infections:

1. Good hand washing, especially after toileting and before meal preparation
2. Screen visitors for illness, especially small children, and particularly within the first 2 months after transplant
3. For the first 2 to 3 months after transplant, designate 1 bath room in the residence for the transplant recipient's sole use, if at all possible
4. It is important to maintain good dental hygiene through regular brushing, flossing, dental screenings and cleanings. It is not recommended to have a cleaning within the first year after transplant
5. Do not clean bird cages, fish or turtle tanks or cat litter boxes. The cat litter box should be covered and taken outside before it is changed
6. Dogs are ok provided that they are kept away from the recipient's incision. Avoid handling any animal waste
7. Maintain the health of your pets with vaccinations, de-worming de-fleeing, etc.
8. For the first 2 months keep your exposure to large crowds at a minimum
9. For the first 2 to 3 months avoid gardening or any activity that involves digging in soil
10. Maintain good nutrition, plenty of rest, and a regular exercise program to promote a higher resistance to illness

B. Signs and Symptoms of Infections:

1. Ulceration's of membranes (i.e. mouth, nose, genital area)
2. Skin eruptions or cuts
3. Fatigue, shortness of breath
4. Cough, increase in sputum
5. Fever > 100 F, chills
6. Redness, swelling, drainage

If you develop symptoms of an infection that is getting progressively worse, please contact your primary care physician first, and then notify the transplant clinic.

VIII. INFECTION: CONT'D

C. Types of Infections:

1. Viral infections – Cytomegalovirus Virus (CMV), Herpes-simplex Virus type I (cold sores and blisters around the mouth); Herpes-simplex Virus II (genital sores and is transmitted sexually); Herpes Zoster (shingles, small water blisters)
2. Fungal infections – Candida (yeast in the mouth or throat also called thrush, or vaginal)
3. Bacterial infections – Usually occur where there is a break in the skin, and are noted to exhibit redness, swelling, tenderness, or drainage

D. Vaccinations:

1. No vaccines within the first year after transplant or within 6 months of a rejection episode
2. **No live vaccines ever**
3. If in contact with small children who are of vaccination age, be aware that they may be receiving live vaccines, and that the live virus is shed in the stool of that child for up to three after the vaccine is given.

IX. MALIGNANCIES:

Another risk of transplantation is an increased risk of malignancies. The immunosuppressive medication hinders your body's natural ability to patrol and destroy abnormal cells.

A. **Routine Screens:** For early detection of malignancies it will be important to have a few routine screens, and to follow some common sense rules. If you find anything unusual you must notify your transplant team immediately.

1. Women should have yearly PAP smears
2. Women should have bi-yearly mammograms if over 35 years of age
3. Men should have prostate exams every year if over 50 years of age
4. All transplant recipients over the age of 50 should have a sigmoidoscopy (rectal scope) every other year
5. All transplant recipients should perform a Lump-'n-bump check once a month while in the shower. Check your body for unusual bumps, lumps, skin discolorations, etc.

IX. MALIGNANCIES: CONT'D

B. **Sun Hazard:** Many of the medications that you are taking as a transplant recipient can increase the effects of the sun, it is therefore important to take some precautions to minimize your exposure to the sun.

1. Apply sunscreen with SPF of at least 15 every day, come rain or shine, and apply it often. The effects of sunscreen come from the build up of the sunscreen on your skin. So make it a part of your daily routine.
2. If you are going to be out in the sun for prolonged periods of time, be sure to wear a hat with a brim to help shade your face, and keep your arms and legs covered
3. Avoid prolonged periods of time in direct sun light, especially during the hottest time of the day

X. LAB TESTS:

Lab tests monitor your kidney function, blood cell counts, levels of medication and electrolytes (minerals) in your blood stream.

A. **Blood Cell Counts:**

1. White Blood Cells (WBC) – an increase can be a sign of infection, a decrease can be a potential side-effect of the CellCept/Myfortic
2. Hematocrit (Hct) - measures the percentage of red blood in your blood. The red blood cells carry oxygen to all parts of the body
3. Hemoglobin (Hgb) – measures the amount of oxygen carrying hemoglobin in the blood. When your Hct and Hgb are low you may feel tired or have little energy a blood transfusion may be necessary. If they are too high, removal of blood through a procedure called a phlebotomy may be necessary
4. Blood Urea Nitrogen (BUN) and Creatinine (Cr) – Tell how well the kidneys are working, by measuring the waste products that they are supposed to remove from your body
5. Calcium (Ca), Magnesium (Mg), Potassium (K), Sodium (Na), Phosphorus (phos), Carbon Dioxide (CO2) – are all electrolytes that maintain the normal functioning of the body
6. Glucose (Gluc) – measures the blood sugar level. An elevation in blood sugar if it occurs while fasting is a sign of diabetes. The prednisone that you have to take to prevent rejection can cause your blood sugar level to rise, this is referred to a steroid-induced diabetes

XI. RESUMING NORMAL ACTIVITIES:

The time until the resumption of normal activities varies from person to person. Below will follow a few general guidelines for you to follow. If you have any more specific questions or concerns, please be sure to consult your transplant team.

A. Diet and Nutrition:

Cholesterol blood levels can be reduced by changing the kinds of fats eaten, and by avoiding cholesterol rich foods, e.g. eggs, beef, organ meats, shellfish, and whole fat dairy products. A nutritionist and an exercise physician will be available to work with you to formulate a diet plan, and exercise program.

1. Sodium (salt) – A low-sodium diet is recommended. Prednisone and salt cause you to retain water, which causes your blood pressure to go up. Beware of processed foods and some over-the-counter medications which can contain high amounts of sodium
2. Fat – Since transplanted hearts are at increased risk of developing atherosclerosis, you will need to follow a low-fat diet to decrease the chances of developing coronary artery disease
 - Saturated fats – are bad fats, they raise blood cholesterol levels. For example; whole milk, butter, coconut oil, solid shortening, and regular cream cheese
 - Monosaturated fats – these fats may help reduce cholesterol levels, for example; olive oil
 - Polyunsaturated fats – are good fats that help to decrease blood cholesterol levels. They are found in liquid oils e.g.; corn, cottonseed, safflower, and soy oils
3. Sugar – in general a reduced sugar intake is recommended. Highly refined foods, i.e. cookies, cakes, etc., while providing a quick source of energy are devoid of nutritional value and lead to weight gain. If you are a steroid induced diabetic then these sugars need to be avoided completely

XI. RESUMING NORMAL ACTIVITIES: CONT'D

B. Exercise:

Rehabilitation will begin 4-6 weeks after surgery. The purpose of your exercise program is to provide a gradual activity plan tailored to your individual needs, which will enable you to resume your normal activities. Your progress will be dependent on motivation, your pre-transplant level of activity, age, and post-surgical course. The benefits of exercise are multiple: maintenance of ideal body weight, feeling physically stronger, feeling mentally more alert, improving the efficiency of your heart function . Following the rehabilitation period you should ideally exercise at least 3-5 times per week, on a regular basis. Please remember that due to denervation of your transplanted heart your heart rate will increase more slowly, therefore you should always have a well defined warm-up and cool-down program.

C. Driving:

Usually you can drive a car 4-6 weeks after discharge from the hospital. You can ask a transplant surgeon during your clinic appointment when you can resume driving.

D. Returning to Work:

Your return to work date will depend on many factors, e.g. pre-transplant activity level, rejection occurrences, age, post-surgical course, and type of work. Check with your transplant coordinator or transplant physician for clearance to resume employment.

E. Sexual Activity/Pregnancy:

Sexual activity will not harm your transplanted heart. As is the case after any major surgery wait at least 6 weeks (or when it is comfortable) before engaging in sexual intercourse. If you are sexually active and do not have a steady partner, it is essential to use condoms to reduce the risk of sexually transmitted diseases such as AIDS, syphilis, herpes, hepatitis, or gonorrhea. We advise all sexually active women to have routine gynecological examinations yearly, which includes PAP smears. It is recommended that all women in the child bearing age group who are sexually active use birth control. Pregnancy is an additional risk to the transplanted organ. If you are thinking of having a child, feel free to talk with your transplant team.

XI. RESUMING NORMAL ACTIVITIES: CONT'D

F. **Dental Care:**

Prior to having dental work (which includes a routine cleaning), it will be necessary for you receive a short course of antibiotics. This is because of your increased risk of infection. Your transplant team will prescribe these antibiotics for you. A routine check-up by a dentist and tooth cleaning is recommended every 6 months after the first year post-transplant.

G. **Immunizations:**

It is recommended that you receive a yearly flu-shot after your first year of transplant, only if you are healthy (not experiencing a major infection or rejection). **YOU MAY NEVER RECEIVE A LIVE VACCINE.**

H. **Skin and Hair Care:**

You will not need any special skin care, unless you develop acne or dry skin. Generally, you should shower or bathe as often as necessary to keep your skin clean. Most soaps are appropriate. Some problems with your skin and hair can develop because of the medications you take to prevent rejection. Notify your transplant team if you discover any unusual skin growths, rashes, or discolorations. The specific problems are discussed below:

1. Acne – Prednisone can cause acne on your face, chest, shoulders, or back. Neoral (cyclosporine) can make your skin more oily. If acne develops, wash the area more frequently with a mild soap, scrubbing gently with a clean, wet washcloth. Rinse the soap completely from your skin to leave the pores open and clean. If the acne does not respond to this treatment, you can discuss specific acne medications with a transplant physician.
3. Dry Skin Care – If you have problems with dry skin, use a mild soap and apply body lotion after bathing.
4. Cuts and Scratches – Wash minor cuts and scratches daily with soap and water. For treatment of large cuts, contact your physician immediately.
5. Unwanted Hair Growth – If facial hair increases, use a hair removal cream (depilatory). Be sure to follow directions carefully to avoid eye or lip irritation. Even if hair growth is excessive, do not alter your medications. Contact your transplant team.

XI. RESUMING NORMAL ACTIVITIES: CONT'D

I. Vacations and Travel:

If you are planning a trip to a foreign country that requires immunization for smallpox, measles, German measles, or any other live virus vaccine, ask your transplant coordinator. The transplant team can give you a medical release if necessary. If you are traveling out-of-state, or out-of-country, ask your transplant coordinator for the name and telephone number of the closest transplant hospital.

You may feel overwhelmed with all the information you need to learn about your transplanted organ. Remember, a transplant coordinator is available for routine calls during office hours (Monday through Friday 8:30 am to 4:30 pm). In addition, a coordinator is always on call 24 hours a day, 7 days a week for concerns, problems, and questions. To contact the on call coordinator call the office at (916) 733-8133 or (800) 556-8133

NOTICE OF NONDISCRIMINATION

Sutter Medical Center, Sacramento does not discriminate against any person on the basis of sex, disability, age, diagnosis, economic status, educational background, race, color, ethnicity, religion, ancestry, national origin, sexual orientation, marital status, or source of payment for care, whether the services provided are carried out by SMCS directly or through a contractor or any other entity with whom SMCS arranges to carry out its programs and activities.

If this facility provides emergency services, it must not deny those services to a person who needs them but cannot pay for them.

For further information about this policy, or in the event you wish to file a complaint alleging violations of the above, please contact:

Sutter Medical Center, Sacramento
Integrated Quality Services Coordinator
Telephone Number: 916-733-3075
TDD: 916-454-2277

You may also file a complaint regarding any allegation of discrimination on the basis of sex, age, disability, race, color and national origin with the following agency:

Office for Civil Rights
U. S. Department of Health and Human Services
50 United Nations Plaza, Room 322
San Francisco, California 94102

Telephone Number: 415-437-8310

TDD Number: 415-437-8311 Fax Number: 415-437-8329