

CANCER
OUTREACH and
RELIEF
EFFORT

A Community Service Project Sponsored by the
American Medical Student Association

INTRODUCTION

C.O.R.E. stands for Cancer Outreach and Relief Effort, which is a community service project, sponsored by the American Medical Student Association. CORE pairs medical students with pediatric oncology patients and their siblings. The program is intended to provide individual emotional support for the patients and their siblings as well as relief for their parents. It also allows medical students to gain a better understanding of the issues involved in chronic illness.

Carol Karp founded CORE approximately eight years ago at Brown University, and the program has been quite successful there. At the AMSA National Convention in 1989 Patricia Anastasio and Mark Shane became project coordinators and were very enthusiastic about starting a program at their school, the University of South Florida College of Medicine. They decided to document their process, step by step, in order to develop a guide to instruct other students on how to begin similar programs at medical schools all over the country.

Because circumstances will differ from school to school, this is only intended to be a guide. Variations can be made to fit the needs of your specific situation. For example, the University of South Florida College of Medicine is closely affiliated with the Children's Cancer Center at the H. Lee Moffitt Cancer Center and Research Institute. This Center also cares for children with hemophilia and sickle cell anemia. Therefore, the program there includes children with these illnesses as well as patients with all types of cancer

GETTING STARTED

First, decide who will be involved in the program and exactly what you want to accomplish. It takes at least three people to start the program. A student coordinator is needed to organize and inform the students. A faculty advisor is needed to be a liaison between the medical school and the hospital/medical center and to give advice on specific medical issues. A patient coordinator is needed to organize and inform the patients and their families. This may be a psychologist, social worker or some other special employee of the hospital/medical center who knows the details and specific needs of the patients and their families.

SAMPLE PROGRAM PRINCIPLES

H. Lee Moffitt Cancer Center and Research Institute

Medical Student Big Brother/Big Sister Program

I. Purpose

To provide individual emotional support for pediatric patients and siblings, and to provide the medical students with a better understanding of the issues involved in chronic illness.

II. Scope

This policy and practice applies to all pediatric patients and their siblings and to any USF Medical Student that has completed at least one semester.

III. Responsibility

It will be the joint responsibility of the patient coordinator from H. Lee Moffitt Cancer Center (at this time the Child Life Specialist will be serving in that capacity), the faculty advisor from the University of South Florida Medical School, and the medical student coordinator(s), to implement the program and monitor on an ongoing basis.

It will be the patient coordinators responsibility to contact the pediatric families and to serve as a contact person ongoing.

It will be the medical student coordinators responsibility to contact the medical students and to serve as an ongoing contact person.

IV. Practice

Pediatric Family Involvement:

1. Pediatric families will be contacted by letter and given the opportunity to participate. Participation will be based initially on the availability of medical students.
2. Those families choosing to participate will receive an information packet that further explains the program and includes a permission form. A signed permission form must be returned before participation will be confirmed.
3. An initial information session will be held for parents in order to outline the program and to offer the opportunity for questions.
4. Families participation at all times is voluntary.

Medical Student Involvement

1. Medical students will be informed about the program by letter. The letter will outline the program and contain an application form.
2. Medical students will be asked to make a one-year commitment of at least two hours per week.
3. From the medical students submitting an application, initially fifteen will be selected to participate. At a later date the program will be expanded. Each selected medical student will be matched with a patient or a sibling of the same sex.
4. An initial training session(s) will be held to be followed up by bimonthly support/educa-

tional meetings. The medical student coordinator(s), the faculty advisor, the patient coordinator and all students will be expected to attend.

POLICIES & PROCEDURES

RECRUITING PARTICIPANTS

Once the coordinators and advisors are chosen and the principles of the program have been approved by both the medical school and the hospital/medical center, the next step is to recruit medical student volunteers. The student coordinator(s) may make an announcement to his/her class and hand out applications. When you know exactly how many male and female students would like to participate, the patient coordinator may then proceed to contact the same number of male and female patients and/or siblings.

It was necessary to have the parents sign permission slips releasing the program and all participants from liability for insurance purposes, especially if the students will be transporting the children in their automobiles. Your faculty advisor or patient coordinator can help you find out what is required in your particular situation.

SAMPLE STUDENT APPLICATION FORM

Dear Med II's,

I would like to introduce you to a new program developed by AMSA called the Medical Student Big Brother/Big Sister Program. It involves the pairing of a medical student with a pediatric patient (or sibling) at the H. Lee Moffitt Cancer Center. The purpose of this program is to provide individual emotional support for the pediatric patients and their siblings, and to provide the medical students with a better understanding of the issues invoked in chronic illness.

Because this program is just starting, the number of students must be limited to fifteen. However, once it gets off the ground, it will be expanded. This program involves a one-year commitment of at least 2 hours per week. In addition, an initial training session(s) will be held to be followed up by bimonthly support/educational meetings. The medical student coordinator(s), Patty Anastasia and Mark Shone, the faculty advisor, Dr. Judisch, the patient coordinator, Melanie Hall, and all students will be expected to attend

If you are interested in becoming involved in this new and exciting program, please complete the application and put it in my box by September 15th. I will be sure to contact you shortly thereafter.

Sincerely,

Patty Anastasia

Name _____

Why do you want to become involved with this program? _____

Other activities you are currently involved in _____

I understand that to participate in this program I must have completed at least one semester of medical school and that this program requires a one year commitment.

Signature _____

THE TRAINING SESSION

During the training session students may be given a set of guidelines to let them know what is and isn't expected of them. Parents are also given a set of guidelines as to what is and is not considered reasonable to ask of the students. The guidelines used in the program at U.S.F. C.O.M. were adapted, with permission, from the guidelines used by the Hillsborough County Big Brother/Big Sister Association.

Students may then be given an overview of the physical and emotional aspects of the types of illnesses they will be dealing with. They can be taught about mediports and hair loss, as well as the developmental stages of different ages. These issues and any others of concern can be discussed in more depth during the following support meetings.

Next each student is given the name, address and phone number of his/her patient or sibling. In the program at U.S.F. C.O.M. the patient coordinator, Melanie Hall, also gave each student a detailed description of that particular family's specific situation. It is advised that the first one or two meetings be held in the child's home (or hospital room) with the parents present so that everyone can get to know and feel comfortable with each other before the student takes the child out. Suggested activities include going to the park/beach and playing ball or frisbee, going to the movies, playing putt putt golf, cards or games, or just talking. An alternative option is to have an introductory picnic where all the students meet their patients/siblings at one time and then let the pairs go off on their own after that

SAMPLE PARENT PERMISSION FORM

My Child, _____ has permission to participate in the Medical Student Big Brother/Big Sister program.

I hereby release the Children's Cancer Center and H. Lee Moffitt Cancer Center and Research Institute for any and all damages occurring during or due to this program.

This release has been given by the undersigned knowingly and willingly in return for the above described service. I have been informed that participation voluntary and I may withdraw at any time.

(Parent's signature)

(Date)

SAMPLE OUTLINE FOR STUDENT TRAINING

1. Guidelines of the program
 - A. Expectations
 1. of the parents
 2. of the children
 3. of the students

- II. Overview of Patient Population
 - A. Brief description of
 1. oncology
 2. hemophilia
 3. sickle cell

 - B. Psychosocial aspects of chronic illness
 1. parents
 2. patients
 3. siblings

- III. Practical Suggestions
 - A. Physical aspects what to expect
 - B. Developmental issues at different stages
 - C. Suggestions for activities
 - D. Tour of C.C. and pediatrics

**MEDICAL STUDENT
BIG BROTHER/BIG SISTER PROGRAM
SAMPLE GUIDELINES
FOR MEDICAL STUDENTS**

1. Be consistent and dependable. Your Little Brother or Little Sister must LEARN to trust you. Specifically, that means: don't oversleep, break dates, nor make promises you can't keep.
2. Do not discuss your Little Brother's or Little Sister's problems in front of him or her (not even with his/her parent).
3. Always be supportive of the parent—even when you disagree. Don't make judgments concerning any family situation. It is, however, appropriate for the Big Brother or Big Sister to correct misbehavior within the context of the relationship, but leave "parenting" to the parent—do not interfere if the parent disciplines the Little Brother or Little Sister in your presence.
4. Don't try to be: Santa Claus to the child or parent, a taxicab service, a probation officer, a "child-saver," a "parent rehabilitator."
5. It is suggested that you not include any outside person on your outings with your Little Brother or Little Sister at least for the first two months of the relationship. Be sure to let your Little know ahead of time and see how they and their parents feel about an outside person. Remember that the Little trusts you as a confidante. Never betray the confidence.
6. Let your Little Brother or Little Sister share in making decisions about the activities in which the two of you engage.
7. Always call the little Brother or Little Sister before you pick him/her up. Be sure he/she gets mother's approval of the day and time before you hang up. Try to give the Little Brother or Little Sister some idea about what you'll be doing so that he/she can be appropriately dressed. And always return your Little Brother or Little Sister home at the agreed time. When you cannot, give that parent a call.
8. Feel free to say no to any and all outlandish requests; e.g., mother asks to borrow money.
9. Don't give the child your phone number without careful consideration first.
10. Do not allow yourself to become over-involved with your Little Brother/Little Sister or any other family member. Vacations, trips, love relationships, etc. may not be engaged in while you are a member of this program.
11. Confidentiality. Do not discuss the name or condition of your Little Brother or Little Sister with anyone outside of the support group, especially the media.
12. We trust you, be yourself.

**MEDICAL STUDENT
BIG BROTHER/BIG SISTER PROGRAM
SAMPLE GUIDELINES FOR PARENTS**

1. Be sensitive to requests that you may make of your child's Big Brother/Big Sister. Do not ask them to borrow money, transport you/your child regularly, babysit or to buy items for you/your child.
2. Please don't discuss your child with the Big Brother/Big Sister in the presence of your child. If you think there is something they should know, call them when your child is away.
3. Try to help your child be considerate of their Big Brother/Big Sister, such as remembering birthdays, saying thank-you, etc.
4. Respect the relationship between your child and their Big Brother/Big Sister. Avoid excessive quizzing and judgments. This is your child's relationship, and it needs to remain a little private in order to be special.
5. If there is something about that relationship that concerns you, contact Melanie Hall immediately.
6. Try to let the medical student know once in a while that their efforts are appreciated.
7. Remember, the relationship that exists is between the child and their Big Brother/Big Sister. Don't ask that siblings or yourself be included on their outings.
8. Do not deprive your child of their weekly visit with their friend as a means of discipline.
9. Make a point of being home when the Big Brother/Big Sister has planned on returning with your child or make arrangements for someone to be there.
10. Be flexible! Remember that the medical student has a busy schedule, too!
11. Give it time. This relationship needs time to develop. So, don't judge it too quickly or expect too much too soon.
12. Your child's Big Brother/Big Sister is a person too! Get to know them at least to the degree that you feel comfortable with them.
13. Unless the plans are specifically to go out to eat, be sure your child has eaten prior to going out with their big Brother/Big Sister.

If you have any concerns, questions or suggestions at any time during the program, please contact Melanie Hall at 972-8430.

SUPPORT MEETINGS

Approximately every month a support/educational meeting should be held. Participants include all students, the patient and student coordinators, the faculty advisor and at times, special guest speakers. During these sessions students can share their experiences, discuss problems and ask questions. Mini-lectures can be given on various topics of interest, movies can be shown and advice can be given.

CLOSURE

At the end of the year a farewell picnic may be held to signify to both the student and the patient/sibling the ending of their special relationship. The children may write a thank you note to the students. The students may write letters to their kids. These may be exchanged at the picnic along with pictures taken to keep as mementos of their special friendships and the time they spent together.

COMMUNITY INVOLVEMENT

The possibilities involved with this program are practically unlimited and its potential for success is great. For example, this program can easily be expanded to include pre-medical students. The program started at the U.S.F. C.O.M. has been met with support and enthusiasm. Articles have been written about the program in local newspapers and various other publications and it may soon be featured in a human-interest segment on local television. And last but not least, in these times of increasing mistrust and malpractice, a program like this where physicians-to-be volunteer their time to needy members of the community helps to show the public just how much we really care about their well being.

PSYCHOSOCIAL ASPECTS

Patients benefit from this program by having a special non-parent relationship. Many times children have concerns that they don't want to tell their parents about for fear of upsetting them. Kids try to be brave and strong in front of their parents. Having a special friend gives them someone to share their worries with. It also gives chronically ill children a chance to participate in some normal activities that might otherwise be missed.

Siblings may benefit from the extra attention a student can give even more than the patients do. Often when one child in a family is ill, the parents must spend so much time caring for and worrying about that child that they may unknowingly neglect the others. This could lead to jealousy or emotional scars that may persist long after the crisis is over. Students can help prevent this by making the sibling feel singled out and special.

Parents are perhaps the biggest supporters of this program. Besides giving them much needed relief and respite, the program benefits the family by giving the children a special relationship outside of the home. Some parents also enjoy teaching the medical students about their children.

The program gives students the opportunity to -have a special one-on-one relationship with a child, sometimes for their first time. They learn to become comfortable around chronically ill kids and to see them as normal, instead of being afraid of them. And sharing experiences during support meetings allows everyone to learn about patient versus sibling issues and issues involved with different diseases even if they don't experience it all directly.

For further information call the AMSA National Office for the name of the current Death & Dying National Coordinators. (703) 620-6600.