

Coping with Cancer *By Timothy M. Buehner, Ph.D.*

In life, there are no guarantees. This becomes painfully evident when a child is diagnosed with cancer. Our assumptions, security, and world view are dramatically altered when the health and life of someone we love is threatened. As parents, we believe the safety and security of our children is our responsibility. We teach them to brush their teeth to protect them from tooth decay. We teach them to not take candy from strangers to protect them from being harmed or mistreated by other people. In reality, as parents, we have no definitive protection against cancer. Subsequently, when a child is diagnosed with cancer, parents (and grandparents) often feel

a sense of helplessness and fear, similar to the reactions of people who suffer through other traumatic events.

Being told you or a loved one has cancer is a traumatic event. Furthermore, it has a traumatic effect not only on the person with cancer, but on the person's entire family. The repercussions of the illness, its treatment, and its outcome are felt throughout the family and affect the daily functioning of each individual as well as the family system. Families, like other systems, seek an equilibrium, or balance. When an external stressor, like cancer, impacts the system, the family must somehow adapt to the new stress, and reestablish a sense of balance.

WHAT'S NEW

Families are often unaware that their "system" is out of balance. Signs of family system imbalance include:

- An increase of discord among family members
- A decrease in performance at work or in school
- A change in behaviors, such as tantrums, bed-wetting, or insomnia
- A change in appetite
- Hyper-emotionality (an increase in emotional sensitivity and behaviors, such as crying or yelling)

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EXPRESSIONS

Early Education Opportunities for Visually Impaired Children *By Nancy Beausir*

On July 21, 1998, my son, Jacob, was diagnosed with bilateral retinoblastoma. At age two, Jacob showed no outward signs of developmental delays from his sight impairment. However, at the time of diagnosis, Jake had little or no vision in his left eye and only used the peripheral vision in his right eye.

My concern as a mother was that when it came time to learn to read and write, he would be faced with some challenges. I asked my pediatrician if there were programs available that could screen him for potential delays. She gave me the number of the Early Intervention Program in my area, Pinellas County.

When I explained Jacob's visual impairment to them, they referred me to the Pinellas Center for the Visually Impaired. They had a program for young children and they were able to assess Jacob's development on all levels, including sight, language and motor skills.

A wonderful teacher began working with Jacob once a week, teaching him shapes and colors among many other things. This teacher suggested that I contact the school system. I was surprised to learn that our public schools offer incredible services to children before starting kindergarten. Because Jacob is at risk for delays in reading and

writing, he was accepted into the Exceptional Student Education Program and now has a teacher who works with him one hour a week at home. This service is funded by the school system.

When it comes time for pre-school, I have two choices. I can either enroll him in the government-funded pre-K program or I can send him to a preschool of my choice at my expense and the school system will pay for a special teacher to come to the preschool to work with him.

If you would like more informa-

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Early Education Opportunities for Visually Impaired Children

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tion or would like to receive a booklet that outlines all the services provided by the government, write to:

Florida's Educational Opportunities for the
Sensory Impaired
Division of Public Schools
Bureau of Education for Exceptional Students
Florida Department of Education
Tallahassee, FL 32399-0400

Families that live in or near Pinellas County can

contact the Early Intervention Program at 727-892-4403 or the Pinellas Center for the Visually Impaired at 727-544-4433.

For those families that live in Miami-Dade County, contact Marrieta Perez at the Division of Exceptional Student Education in the Pre-kindergarten Program at 305-271-9881. For assistance with children in grades 1-12, contact the Division of Exceptional Students Education directly at 305-995-1890 or 305-995-1721.

Coping with Cancer

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Emotional or behavioral withdrawal

Over time, most families are able to adapt to the illness by incorporating it and its effects into the way the family makes sense of the world. How quickly a family is able to do this is dependent upon many factors including:

- The prognosis, treatment and course of the illness
- The prior level of family functioning
- The amount of parental insight into their own, as well as their children's reactions
- The availability and use of social support systems

A variety of therapies and activities can promote a family's use of adaptive coping strategies. For families having a difficult time adjusting to the illness of a child, these therapies can provide them with the tools to move forward in the coping and recovery process. For families that have adequate resources to cope "on their own", periodic counseling can actually accelerate the recovery process.

For adults, adolescents, and older children, traditional family or individual counseling is effective. For younger children, art, play, and music therapy can have similar benefits. The benefits of these therapies occur at the family level as well as at the individual level. At the family level, these therapies:

- Improve intra-family communication
- Decrease the likelihood of one family member becoming identified as the source of the family's problems.

For an individual, these therapies:

- Decrease feelings of isolation
- Provide an opportunity to ventilate feelings
- Improve individual coping abilities
- Improve socialization skills
- Improve interpersonal relationships with medical personnel and family members
- Provide a sense of control and mastery that may otherwise be lost while involved in ongoing treatment

When combined with social support and existing coping strategies, counseling and other therapies can have a significant impact in helping families recover from the initial trauma of having a child diagnosed with cancer. For further information about these therapies, feel free to contact The Courtelis Center, University of Miami, at 305-243-4129, or <http://www.miami.edu/courteliscenter>.

Dr. Timothy Buehner volunteered his time to help support the families of children with retinoblastoma. All of our families and the staff at Bascom Palmer thank Dr. Buehner for his time and efforts in helping us cope with the emotions that occur when faced with a child or loved one diagnosed with cancer.

Dr. Elizabeth Thomas will continue in his place.



**MARK
YOUR
CALENDAR!**



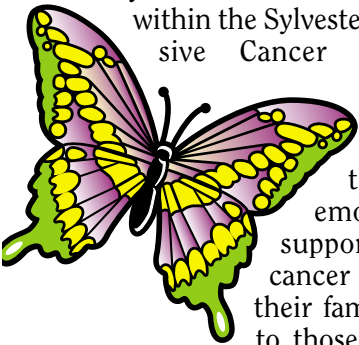
**Our
Annual
Picnic**

FEBRUARY 2, 2002

*Watch your mail
for more details or
call Nicole at
305-326-6072.*

Healing the Mind and the Body

by Nicole Cicciarelli



The Courtelis Center for Research and Treatment in Psychosocial Oncology is located within the Sylvester Comprehensive Cancer Center. The Courtelis Center is dedicated to the special emotional and support needs of cancer patients and their families and also to those patients who have life adjustment issues with other illnesses such as chronic pain.

The psychosocial oncology team includes massage therapists, acupuncturists, mental health counselors, nutritional and pastoral services. These specialists work together with the oncologist.

One of their psychologists, Dr. Elizabeth Thomas, has volunteered her time and joined the oncology team at the Bascom Palmer Eye Institute. Dr. Thomas is a psychologist with a specialization in Clinical Psychology. One of Dr. Thomas's

areas of concentration is involved with a mind-body study at the University of Miami studying the effects of stress management on the psychological and immune systems of people with cancer.

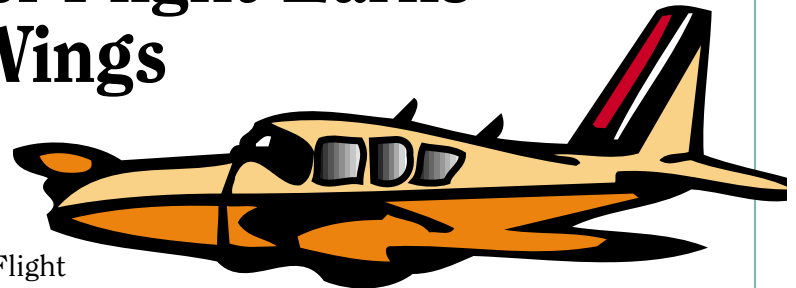
Medical studies have shown that emotional well-being and positive expectations enhance your body's ability to fight disease and recover health. This may be particularly



true for cancer patients. Dr. Thomas continues to provide assistance and support to our patients, their families and also to the staff in handling the emotional stress that occurs when taking care of a family member or a patient who is diagnosed with a life-threatening illness.

If you would like more information about the Courtelis Center, please call 305-243-4129.

Angel Flight Earns Its Wings



Angel Flight is comprised of a group of pilots and non-pilot volunteers who have assisted many of our patients and their families with transportation. They are a non-profit, tax-exempt organization arranging free air transportation to and from treatment facilities for those with medical needs who are financially distressed or unable to travel on public transportation. Service is provided on a non-emergency basis for patients who are stable and ambulatory.

Angel Flight coordinates travel to distant facilities when commercial service is not available, impractical or simply not affordable. Most of the aircraft used by Angel Flight pilots are 4-6 seat General Aviation aircraft that have range and weight limitations.

Angel Flight has played a major role in the transportation of a large number of patients who would otherwise be unable to receive care at the University of Miami/Bascom Palmer Eye Institute, Ocular Oncology service. The service that Angel Flight provides has been invaluable to these patients and they continue to be an essential participant in the treatment plan of many of our patients.



If you would like more information about Angel Flight, you can contact them at 800-FLA-HALO (800-352-4256) or visit their Website at www.angelflightse.org.



THE NATIONAL
RETINOBLASTOMA
RESEARCH & SUPPORT
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Meeting The Challenge of Children's Eye Cancer

If you are interested in helping us develop an informative and supportive website, please contact Nicole at **305-326-6072**.



Blake Norush, age 5.



Brian Pigeon, age 17 with Mo Vaughn.



Carlins Almonor, age 1.



Jonas Taylor, age 4, with baby sister Cora.



Rose Lawrence, age 9.



Matt Winston, age 16, playing bass.

A special
Thank you

to all of the patients and families who have sent
pictures and stories.

A Father's Love

By Duane Ellifritt

EXPRESSIONS

Last Friday, I took my two babies, my son Victor and my daughter Ploy for their cancer check-up. We arrived as usual at 6:00 am at Bascom Palmer Eye Institute. After the routine registration and check in, we headed up to surgery on the sixth floor. The examination under anesthesia or EUA that my children are scheduled for is considered a surgical procedure. We are assigned to room 609 with two other families. There are a lot of babies here today — more than usual. All the babies arrive at 6:00 am and are then assigned a sequence number based on age, and other things. In our room is Cody from Clearwater, Florida, with his parents, my two children and a 19-month-old boy named Luca with his mother, Emilia.

As expected, we wait for hours for our turn. In our room, Cody is up first. They take the babies to the operating room after giving them a “cocktail” that makes them “woozy.” The theory is that if they are woozy, then they somehow do not suffer the separation trauma of being taken from mommy and daddy. Then we must wait about 30 minutes. Generally, all are respectful in the room and quiet during this period, leaving the parents to their thoughts.

They come and take Ploy and Victor. The “cocktail” does not work

very well on Victor and he screams down the entire hallway. While we wait, Luca continues to play on the floor. He is a very cute boy and does not appear shy. He has lovely blue eyes.

Finally, Dr. Murray returns and, as usual, he makes a bee-line for me. He looks me straight in the eyes and delivers;” they are great, no problems.” I breathe again; somehow, I just can’t get used to this. I guess Dr. Murray can tell that I am particularly sensitive about it since I lost an eye to retinoblastoma.

Dr. Murray is a very caring and loving doctor. Experienced at this, his technique is to tell you the results face to face, good or bad, and then follow through with a hug.

We always talk with the other parents. The young mother from Argentina had been to another hospital before coming here and meeting Dr. Murray. Luca’s cancer is large and he has been undergoing chemotherapy for it. His mother says he is responding well to treatment and that the tumor is shrinking. Luca is last in our room to go to the OR because he is at the highest risk for needing additional time while there.

While we wait, Cody and his parents leave, and the nurses come to take little Luca. Victor and Ploy return, and we begin the usual post-op routine of loving, feeding and calming them. While we are waiting, the nurses come and ask Luca’s mother to step into the room across the hall, which is now vacant since we are among the last remaining patients. This is not good, and Dr. Murray and Nicole, his assistant, join the nurse and Emilia in the room. The exam has not gone well for Luca and they must remove his left eye. Emilia refused to sign the consent form before they took him into the OR and they are now trying to convince her to sign it. I am very uncom-

fortable and we prepare to leave. As we walk out, we pass Emilia in the hall. She is standing by the exit from surgery, waiting for her baby to return. She is quietly crying. I do not know what to say to her as I pass. I, above all others, have a right to speak to her about the loss of an eye, but I have no voice. We pass with only glances.

I have been thinking about this scene for the past few days and it bothers me that I could not speak to Emilia. I am not sure what I felt, or feel, but it is not good. I was glad that my children had good outcomes to their examination but I cried that a child lost his eye. It is a cruel lottery of God that takes the eye of one of four babies in a room in Miami. I tried to tell this story to my father tonight and got pretty choked up. Then it occurred to me that he already knows how this story goes; he learned it in 1964.

I wish I had a second chance to tell Luca’s mother that it will be all right. Luca will be all right and someday he too will build his own rockets.

Duane Ellifritt is the Engineering Manager for Boeing on the Delta IV program at Cape Canaveral Air Force Station. He is also a survivor of retinoblastoma.



EXPRESSIONS is a recurring

forum for your thoughts,

comments and ideas. Please

share your views with us.

We want to hear from you!



Jason's Story

By Kay Ruben

Our son Jason was 8 months old when we first noticed something was wrong with his left eye. He had had a bad cold and the doctor had prescribed an antibiotic and cough medicine. I was changing his diaper the first night after he started the medication when I looked down at him and noticed something strange with his eye.

The next morning I called the doctor. I explained the cat's eye effect I saw in his left eye and they thought that he was having a reaction to the cough medications. I took him off the medications but still noticed the effect.

I finally got him in to see the doctor but he still did not see it. He suggested we take Jason to an eye doctor. He referred us to a doctor who could not see him till early February (this was early January 1996). He did not express any emergency in seeing the ophthalmologist.

It was a month later that Joel took Jason for his regular check-up appointment which was one week before the appointment with the ophthalmologist. He called me at work and told me that the doctor wanted Jason to be seen immediately by Dr. Robert Hered from Nemours Children's Clinic in Jacksonville,

Florida.

Dr. Hered explained to us that Jason had a large tumor in his left eye on the retina and the retina was detached. He believed that it had been there for the past four months. He had no sight in his left eye. He then told us he wanted Jason to have an examination under anesthesia the next day.

Jason had his left eye removed and now has a prosthetic eye that he takes out all the time and once fed to our dog. He had three small tumors in his right eye that the doctors treated with cryotherapy. On the last EUA, in October 1997 he had no recurrence of any tumors. We were thrilled until a little girl who also had an EUA that day and had been clear for 2 years, developed another small tumor. We felt that our nightmare was just beginning and we were sinking fast.

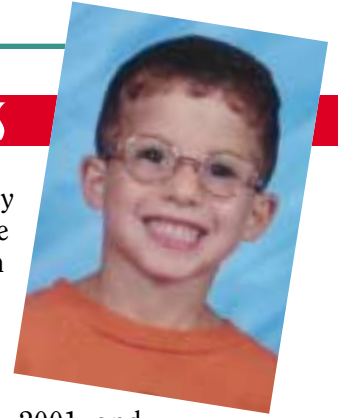
When Dr. Hered first asked if we wanted to talk to other parents we felt that we could handle this ourselves. This was all going to go away. Now, I want to talk, to find out how everyone else is handling it and to see if there is a way we can help each other.

I moved my sons back to South Florida. Dr. Hered recommended that Jason follow up with Dr. Timothy

Murray at the Bascom Palmer Eye Institute.

It is now July 2001 and Jason is 6 years old with no further recurrence since mid-1997. Jason is a wonder. No one notices anything different about him but if someone suspects something is wrong with his eye, he would just walk up to him or her and say, "I have a glass eye, want to see it?" Then he proceeds to ask me to take it out for him so he can show it. Thank God he hasn't tried to take it out himself.

He wants to try out for soccer in the fall. He doesn't think twice about getting into a brawl with his older brother or taking on anyone else. He is doing well in school and starts the first grade in September. The only problem I seem to have with him is that he keeps on breaking his glasses. I have gone through four pairs during the last school year and the place I bought them from went out of business three months ago. (They had a guarantee on the first pair and kept replacing them. Do you think Jason drove them to bankruptcy?)



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