

# HELPING HANDS

FOR FRIENDS, FAMILY, AND SUPPORTERS OF THE CHILDREN'S GAUCHER RESEARCH FUND



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## THE ONLY THING INCURABLE IS OUR PASSION



"First Day of Pre-School"

## Gregory Austin Macres

### Heaven Birthday

The battle to save our son's life was long and difficult. This battle ultimately ended with the pain of losing him to Gaucher Disease, Type 3. However, our son's soul will live on, as will the souls of all children who have been taken by Gaucher disease. Their souls give us the encouragement and strength to move forward, and to ensure that we continue our quest to find a cure. Our story is just one family's experience. It is not meant to glorify Gregory, or to set our families experience apart. Others have lived with a portion of our hardship, and some have lived with far more. The constant we all share is that none of us can predict what challenges life will provide.

### 10 Year Anniversary Issue

As we reflect over the past ten years we are excited with the progress that has been made by the Children's Gaucher Research Fund. With your support we have raised over \$1.3 Million. With your generous donations we have funded important medical research. With your continued encouragement we have hosted Scientific Conferences bringing together the best and brightest scientists from around the world. Although it was not our original intent, it is now clear that this effort may impact not only Gaucher disease, but a host of diseases that affect the brains in young children.

### Gregory's Legacy

For us this has been a very important endeavor, but it has also been a very personal journey. After losing our son to Gaucher disease in 1997 we were determined that our son's life would have meaning; that his life, his courageous battle, and his eventual passing would have a positive and lasting legacy. People have asked where we find the motivation to pour our energies into this effort. The answer is simple; we look at pictures of our little boy and dream of the day that his legacy is a cure.

Although we have printed many family stories in this newsletter, we have never printed the story of our little Gregory ("Heaven Birthday" below) that was written shortly after his passing in 1997. This 10th anniversary issue is dedicated to our son, and to his legacy.

### Life Is Unpredictable

It was December 21, 1993; at 11 months of age Gregory was admitted into the hospital for testing to determine the cause of his recent health problems. For those two days we shared a room with a gentleman and his three year old daughter. Just weeks prior she was brought to the doctor for a routine visit due to a 102 degree temperature. Within days it was determined she had leukemia. The look of shock, disbelief and pain was evident on her father's face as she received her first doses of Chemo Therapy. I remember thinking, "what would it be like to learn your child has such a serious and potentially fatal disease"?

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At that point I still believed Gregory's diagnosis and resolution would be fast and painless. Our lives had not endured any major tragedies, and exposure to such was somewhat limited to the likes of "60 Minutes."

Two weeks later Gregory was diagnosed with Gaucher disease (pronounced "Go-Shay"). When this disease is discovered in infancy, as Gregory was, it is always a more severe form of the disease, referred to as Gaucher Type 3. At this point, it was explained, researchers were somewhat limited in their understanding of the disease. Life is unpredictable; a major tragedy in the health of our son. We were no different than those of you reading this article, except now we were also like those we watched on "60 Minutes."

## Difficult Decisions

When Gregory was diagnosed in January, 1994, we did our research and found that the National Institutes of Health (NIH) in Bethesda, Maryland, were conducting studies using an enzyme replacement therapy. Gregory received weekly I.V. infusions of this drug from 1994 through 1996. This was a new drug, and it was not clear if it would be successful on the more severe forms of Gaucher disease that affect young children. Gregory's disease required us to make difficult decisions. Decisions that had to be made based on limited information, with results that were

## Our lives will be forever changed. He taught us to give, is to be fulfilled.

not guaranteed. In December, 1996, just prior to Gregory's 4th birthday, it became clear that more aggressive action was needed. It was decided, despite the risks, that a bone marrow transplant was necessary.

Gregory's sister, 5 year old Ashley Rose, also had decisions to make. Though we did not ultimately use Ashley as a donor, it was necessary to test Ashley as a potential donor of bone marrow. We explained this to her, and we allowed her a few days to make her decision. On the morning before Christmas, 1996, she told us in a shivering, frightened voice, that she was willing to give her bone marrow to her brother. Her first question was, "when are they going to take the tubes out of Gregory's chest, and put them in mine." She had misunderstood, but her love and courage were painfully clear.

Little Gregory succumbed to complications of a Bone Marrow Transplant, and passed away on his sister Ashley's 6th birthday, April 13, 1997. This day will always be Ashley's birthday. This day will always be little Gregory's "Heaven Birthday."

## The Pain of Losing a Child

It is impossible to describe to you the pain of losing a child. If you have children, I am sure you can imagine how painful it is. Perhaps you have lost a child, and you know the pain. There are times that you cry so hard you feel you may lose your mind. These four years were a journey of immense pain, and of unexpected pleasures. Four years that we would wish on no one. Four years that we would not give up for anything in the world.

"He will look down,  
and he will see his  
Mommy and Daddy  
fill this painful void  
with beautiful things."

Those first few months in 1994 after Gregory's diagnosis were difficult. I remember countless nights lying in bed, holding my son, crying, and wondering why. One night I had an embarrassing thought. I said to myself, "If God is going to take my little Gregory, it would be easier if he took him now, instead of when he is 4 years old, when we are so much more attached to him." I was embarrassed even having that fleeting thought. I now thank God for giving us four beautiful years, to become so close to our son. To appreciate who he was, and all that he had to offer. Four years that taught us so much.

## Gregory Gave Us Our Strength

It is important to understand how much he had to endure. The multiple operations. A GT tube in his stomach. A central line in his chest. Weekly I.V. infusions of medicine. Innumerable tests at Kaiser Hospital, at the National Institutes of Health, and at the University of Minnesota. Four years that you would think would make him a sad little boy. This was not the case.

Gregory had a beautiful smile and a precious little dimple. Despite the difficulty of all of his medical problems he was a happy little boy. Gregory also had a great sense of humor. During his Bone Marrow Transplant in Minnesota, his hair was starting to fall out due to the Chemo Therapy and Radiation treatments. We decided to shave his head. We told him he was going to be an army man. We dressed him in daddy's Special Forces T-shirt and played Green Beret Cadence music. Before putting him in front of the mirror the nurse warned us, "he'll probably get frightened, and start to cry." We lifted him up in front of the mirror; he laughed, rubbed his head, and laughed. His good spirits and his sense of humor had an impact on the doctors and nurses who cared for him.

Gregory was one determined little boy. He was speech delayed, and you could just see the determination on his face at speech therapy to say that word or sentence. He was so excited and determined to go to school. On the first day of school he got out of the car, grabbed his lunch box, and marched toward the building. His mother quickly locked up the car and chased after him. He turned to her, and in that little independent voice, said "No, Done, Bye."

As a parent of a chronically ill child, the sleepless nights, the constant medical care, and the emotional stress, can bring you down and can tempt you with self pity. When your child rejects hopelessness, shows resilience and a love for life, you are provided with the strength to rise to the occasion and live up to the challenge. Gregory gave us our strength.



“Four years that we would wish on no one. Four years that we would not give up for anything in the world.”



## Gregory Taught Us About Life

Gregory taught us how selfless we could become. All parents know that selfless devotion which grows within upon the birth of a beautiful child. That selflessness was brought to a peak one Sunday morning in the emergency room at Kaiser Hospital in Santa Clara, California. Gregory was “crashing” from a blood infection however in the emergency room that morning it was yet to be determined. As his naked body lay on the sterile white paper, tired and shivering from fever, I sat on a stool as the doctors and nurses scurried back and forth in obvious concern. As I drifted off into a dream-like state I had a conversation with God. I asked that Gregory take my health, and that I take his medical problems. There was no hesitation, there were no second thoughts. It was a feeling, a complete feeling of selflessness, never before experienced.

Gregory taught us a new way to fulfillment. Prior to his illness we derived fulfillment from receiving; a new car, a hockey game, a vacation. We soon found fulfillment from giving; research, medical care, therapies. He helped us find the strength to rise to the occasion, and we soon found pleasure and fulfillment in the challenge. Our lives will be forever changed. He taught us to give, is to be fulfilled.

## Our Faith Is Stronger Now

After Gregory’s passing at the University of Minnesota we drove for 2.5 days home to California. To us HWY 80 will always be a “trail of tears.” We talked and we cried. We were so confident that Gregory would have a chance at life. We were so prepared to do what needed to be done. To care for Gregory after his bone marrow transplant; to spend the years of time and effort to help him to be healthy and to catch-up developmentally.

In the back of your mind you know the day might come that you lose your child. You have many conversations with God. You beg, you plead, you bargain, you cry. You insist that God show himself, that he sit at the end of your bed so that you can ask, “why?” When you lose your child this process repeats itself, however with increased intensity. We often wondered how we would react to God if we lost little Gregory. After so many years of hard work, dedication, and love, we were not sure of our reaction.

We lost our little boy on April 13, 1997. Despite our loss, our faith has grown stronger. We are not resentful. We are not bitter. We believe God is good, and we believe God is full of love. You may ask, “You lost your son, who you loved so very much, where is God’s goodness and love?” We believe God is the source of goodness and love, and the essence of such he shows through his children. His children are family, friends, neighbors, doctors, nurses, and people like you. People who have offered so much love and support. Those who acknowledged our battle and offered kind words of encouragement. The hundreds who packed the church at his memorial service. The Donor of bone marrow; a man who was willing to respond so fast, to give part of his body to a little boy he did not even know, so little Gregory would have a chance at life. Complete strangers who offered a phone call, a note, or a prayer; so many were praying. Discussions of faith make some uncomfortable. For those I will say that we do not for a moment believe we have all of the answers. For those I will say that God may not sit on the end of my bed, and there may be a lot of things that we do not understand, but the outpouring of goodness and love has been overwhelming. We believe God shows his goodness and love, through you.



## How Do We Cope

Since Gregory's passing, many have wondered how we cope after such a painful event in our life. Some ask this question, and with some you can read the question on their face. It is impossible to explain the grief and the feeling of loss. There is now a void. It is as though half of your body and half of your soul have been taken away. Quiet moments are now filled with memories, sorrow, and tears. No matter how hard it may be, we will head down the path that we know is the right path. The legacy of our little Gregory will be positive. He will look down, and he will see his Mommy and Daddy fill this painful void with beautiful things. We will continue to be committed to our family, and to each other. We

**This day will always be Ashley's birthday. This day will always be little Gregory's "Heaven Birthday."**

will continue to give. We will raise money for the "Children's Gaucher Research Fund." We will be involved in the research in the coming years. We will fill ourselves with all that defined little Gregory; determination, a sense of humor, a spirit of hope, and an appreciation for each day.

## To Gregory We Say

You taught us "to be a child is to know the joy of living. To have a child is to know the beauty of life." We will always remember your smile, your humor, your determination. Most of all, we will remember your courage. Mommy and Daddy will not be resentful or bitter, and we will not turn our backs on God. There will always be an emptiness inside, but we will fill that emptiness with memories of you. We love you, and we will miss you, until we see you again.

## To All of You We Say

God shows his goodness and love through you. Continue to open your hearts. Do not be afraid to look us in the eye. Do not be afraid to say Gregory's name. Do not be afraid to give us a hug. And do not be embarrassed if we cry.

## "Children's Gaucher Research Fund"

We lost the battle to save little Gregory's life, but we are not ready to accept defeat in battling Gaucher Disease. We have founded the "Children's Gaucher Research Fund" whereby 100% of every dollar donated, goes to medical research. All administrative needs are donated, or paid for by the founders.

As you read this, there are parents somewhere learning that their child has been diagnosed with Gaucher disease. As you read this, there are parents caring for their chronically ill child. As you read this, there are parents mourning the loss of their son or daughter. We hope that you will adopt the "Children's Gaucher Research Fund" as your charity of choice. It is our sincere desire that one day you will know that your contribution played a part in giving life, to thousands of young children.

Written in 1997 by:

*Greg and Deborah Macres*

*Founders - Children's Gaucher Research Fund  
Granite Bay, California*



## Maria Villar—Honors Sister & Raises Funds for Research

Maria Villar, a senior at Charlottesville High School in Charlottesville Virginia, organized a Charity Concert raising over \$3,400 for medical research. The following is Maria's description of the event:

"At the actual concert, after all of the set-up, the first thing that I did was welcome everyone who attended. Then the LifeTeen Band that I am a part of sang a few songs. After that, my piano teacher, Mateo Favero, played a few pieces on the piano. When he finished, we had an intermission for about fifteen minutes so that the audience could enjoy the refreshments we had provided. After the intermission I talked a little bit about why I decided to hold the concert. I had to do a community service project for my Government class, so I decided that it would be a good idea to host a concert that would help fund research for my sister's disease. It is something that has weighed down upon our family and my sister for years. I thought that anything that I could do to help would be great. During my speech my sister came up to the front and thanked everyone for attending. After that an archipelago group from the University of Virginia called CHoosE performed. Then the LifeTeen Band and CHoosE sang a few songs together, and when they finished my Father gave a speech about his experiences with my sister having Gauchers. We raised over \$3,400 at the concert."



From left to right Ms. Jennifer Hilleary (Co-Advisor), Ashley Macres, Greg Macres, Elias Mendoza (Co-Advisor) and Robert Tabares (Ex-Advisor).

## Florin High School Key Club

You really have to be there to experience the excitement, to hear and feel the energy. Over 300 students from Florin High and surrounding High Schools in the Elk Grove Unified School District (Northern California) participated in a Friday night Awake-A-Thon, again raising over \$10,000 for research. In the past five years, these students are approaching over \$50,000 that they have raised for the CGRF. This group of 300 students comprised members of the various High School KEY Clubs (Kiwanis Educating Youth) and they are – smart – polite – full of energy – and keenly interested in making a difference.

We thank Stephen Chan, Jennifer Hilleary, Elias Mendoza, Robert Tabares and all of the KEY Club students for their continued support.

## Jesus Salcedo

### WORKING HIS MAGIC

We would like to thank our graphic designer, Jesus Salcedo, who "Works His Magic" twice a year with our Helping Hands newsletter. Jesus designed this newsletter you are reading, and he provides the other the graphic needs for the CGRF that arise throughout the year. To Jesus we say, "We appreciate your talent, but most important we appreciate your passion and commitment to excellence." Jesus is always there to lend a "Helping Hand."

Jesus works with THINK (formerly Media Resource Advertising) in Northern California as their Senior Designer. As many of you know Media Resource Advertising/THINK is our printer who, since inception of the CGRF, has printed our newsletters and various printed materials free of charge.

## Research Funding To Increase Significantly in 2007

Thanks to your support the Children's Gaucher Research Fund is making significant progress. We have made the decision to increase our funding of medical research and we are now prepared to fund up to \$250,000 per year. We are currently reaching out internationally for research proposals that we will be reviewing in the coming months. Our Scientific Advisory Board will review the research proposals as well as "peer-review" from scientists outside of the board. This is a significant step and a major commitment to research. In the next newsletter we will outline the decisions that have been made in terms of funding additional research.

## 100% TO RESEARCH

You need to know:

1. The CCRF is a *legitimate* IRS approved 501 c3 non-profit organization.
2. *100% of every donation* goes to medical research.
3. We *do not* hire professional fundraising companies who keep 50% of donated funds.
4. We have talented volunteers who *donate* their time and talent for a variety of our needs.
5. All administrative costs are paid for by the *founders*.

Simply put: if you send your hard earned dollars - *It ALL goes to medical research.*

Visit our web site at:

[www.childrensgaucher.org](http://www.childrensgaucher.org)

All family stories can be  
read on the website.

Contributions Payable To:

Children's Gaucher Research Fund

P.O. Box 2123

Granite Bay, California 95746-2123

## 2008 Conference: Lysosomal Diseases and the Brain

The next Lysosomal Diseases and the Brain conference is scheduled for May 29-31, 2008.  
Details can be obtained by visiting [www.Lysosomal-brain-conf.Org](http://www.Lysosomal-brain-conf.Org).

## Children's Gaucher Research Fund



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