In Loving Memory of Selena Marie Rodriguez

100% To Research

You need to know:
1. The CGRF is a legitimate IRS approved 501 (c) 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 needs.
5. All administrative costs are paid for by the founders.

Simple put:
If you send your hard earned dollars – IT ALL goes to medical research.

Not our web site at: www.childrensgaucher.org
All family stories can be read on the website.

Contributions Payable To:
Children's Gaucher Research Fund
PO Box 2133
Grande Bay California 95746-2133

When the Children's Gaucher Research Fund began we had a simple goal to find a cure for a rare orphan disease known as Gaucher disease (Type 2 and Type 3). With the help of volunteers and donors we began raising funds with the hope of funding targeted medical research that would bring to bear the dreams of many.

Limited Research

Children's Gaucher Research Fund was established in 2002 by Dr. Tony Futerman of the Weizmann Institute of Science in Israel. The initial goals of this research were extremely important and were discussed in the September 2003 issue of a major medical journal Nature Review/Neuroscience. Dr. Futerman stated that "The CGRF has made a difference..." The CGRF has made a difference

In 2004 the CGRF in collaboration with the National Institute of Health funded a medical conference in Bethesda, Maryland that attracted over 100 attendees from six different countries. The most memorable event occurred when one of the researchers said, "The similarities between Neuronopathic Gaucher disease and other lysosomal diseases are great, that therapy for Neuronopathic Gaucher disease may impact Gaucher disease itself and the second most common cause of dementia in the world. Thus, the money spent on one disease may have an even greater impact upon a more prevalent scourge of mankind.

Funds Raised

Although earlier than we had anticipated, cosmetic funding it was. Dr. Tony Futerman of the Weizmann Institute of Science in Israel and researchers said, "The similarities between Neuronopathic Gaucher disease and other lysosomal diseases are great, that therapy for Neuronopathic Gaucher disease may impact Gaucher disease itself and the second most common cause of dementia in the world. Thus, the money spent on one disease may have an even greater impact upon a more prevalent scourge of mankind.

Future Research

Researchers today is a position to make a difference for our rare orphan disease. Researchers are beginning to connect the dots to 26 other lysosomal diseases, Parkinson's disease, and perhaps other brain disorders.

Future Research: We ourselves today is a position to make a difference for our rare orphan disease. Researchers are beginning to connect the dots to 26 other lysosomal diseases, Parkinson's disease, and perhaps other brain disorders.

"To those children whose lives have been curtailed by a caprice of nature, yet whose smiles give us hope for the future..."
A New Approach to Treatment of Lysosomal Diseases of the Brain

Dear Friends,

Much has happened since I wrote my first newsletter to the Gaucher community three years ago. The same time could I say that very little has changed, except the name and the address of our newsletter. I have been starting high school. She was healthy. And, like any healthy teenager, she was looking forward to a new season of health. The Cerazyme she took every other day, as prescribed by her doctor, was, as she had been informed, a "chemical chaperone". The therapy consisted of a weekly infusion of Cerazyme, a drug that Ihserstpered the brain, and can be given intravenously or directly into the brain. Therapy for neuronopathic Gaucher disease, the systemic symptoms (in the sense of "a chemical chaperone") are reversible, many of the individual symptoms are reversible. Kristina would be happy to have this same treatment for her. Not just for 5 or 10 years or longer. She would like to live and work full of life, to the end of her days. Maybe it can be a reality for her to go to college and work full-time, a way to continue to develop into the dream. She has been a successful student and a leader in our student council. She has a hole in her heart that she can never be fixed. Kristina is too large to fit into the small space of the brain. Infusion of enzyme into the brain, the liquid accumulating around the brain, the blood-brain barrier. There is a barrier to the brain, the blood-brain barrier. Blood-brain barrier. The barrier to the brain. The liquid accumulating in the brain, the blood-brain barrier. This is not a treatment, it is not a cure. Chemical chaperones may have additional applications. In recent years, evidence has accumulated that this sounds like a success story. Kristina is alive and well. I feel guilty. Kristina is alive and well. I feel guilty. Kristina is alive and well. I feel guilty. Kristina is alive and well. I feel guilty. Kristina is alive and well. I feel guilty. Kristina is alive and well. 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A New Approach to Treatment of Lysosomal Diseases of the Brain

Kristina Caffrey Four Years Later

Dear Friends,

Much has happened since I first met the Berry family in the summer of 2001. Kristina died on March 12, 2005, after suffering from Gaucher disease for most of her life. She was 18 years old. I met her parents, Don and Angel Berry, at a time when they were still hopeful about finding a cure. They had a bright hope that something would be developed to help their daughter and to help other people who suffer from this disease. They have participated in a clinical trial that has given them a sense of hope. They have also been willing to talk about Kristina and her life, their family, and their hope. The family has become a national symbol for Gaucher disease, a disease that is not widely known.

Kristina's story is not unique. Many children suffer from lysosomal diseases, such as Gaucher disease, neuronopathic Gaucher disease, and Fabry disease. These diseases are caused by defects in the genes that code for lysosomal enzymes. The enzymes are involved in the breakdown of lipids, glycans, and other substances. When the enzymes are not produced or function properly, the substances accumulate in the lysosomes, which are cell organelles involved in the breakdown of proteins and other substances.

The most common lysosomal disease is Gaucher disease, which is caused by a deficiency in the enzyme glucocerebrosidase. This enzyme catalyzes the hydrolysis of glucosylceramide, a lipid that is found in lysosomes. Patients with Gaucher disease have an accumulation of glucosylceramide in their tissues, especially in the liver, spleen, and bone marrow.

Kristina was diagnosed with Gaucher disease when she was five months old. She had an accumulation of glucosylceramide in her liver, spleen, and bone marrow, and her blood glucose levels were elevated. She was treated with enzyme replacement therapy, which involves the intravenous infusion of glucocerebrosidase. The treatment was effective in reducing the accumulation of glucosylceramide in her tissues. However, the treatment was expensive and had to be repeated every two weeks. It was also associated with a number of side effects, including chills, fever, and anaphylaxis.

Kristina's disease has changed in the past four years. She has been hospital-free for almost a year and a half. The reason for this is that she and her parents have been able to participate in a clinical trial that involves the use of chemical chaperones.

Chemical chaperones are molecules that are used to promote the correct folding of enzymes in the lysosomes. They prevent the formation of misfolded enzymes, which are toxic to the cell. Chemical chaperones are used in combination with enzyme replacement therapy to increase the stability of the enzymes and to reduce the accumulation of glucosylceramide in the lysosomes.

Kristina's story is a testament to the power of research and to the dedication of her parents. They have worked tirelessly to find a cure for Gaucher disease and to help other families who are affected by this disease. They have been active in the Gaucher disease community and have helped to raise awareness of this disease.

If you would like to learn more about Gaucher disease and the work being done to find a cure, I encourage you to visit the website of the Children's Gaucher Resource Network, which is dedicated to providing information and support to families who are affected by Gaucher disease. The network is also a valuable resource for researchers who are working to find a cure for this disease.

Thank you for your support and for your dedication to finding a cure for Gaucher disease.

Sincerely,

John Carmans Bike Brigade

John Carmans Bike Brigade

5030 Windrose Street

SACRAMENTO, CA 95831

Food and Drink: Italian and Mexican

Tennis: Singles and Doubles

Entertainment: Live Music

Awards: Trophies for the top six finishers among the individuals and teams in each category. A special trophy will be awarded to the teams who come in first in the mixed division.

For more information, please visit the website at www.coldwellbankergolf.com or call 415-762-2222.

2005 Charity Golf Tournament

San Jose, CA

June 26, 2005

Sponsored by the Developmental and Metabolic Neurology Branch

At the National Institutes of Health

The tournament is open to the public and is being held at the San Jose Country Club, where you can enjoy the scenic beauty of the golf course while benefiting a good cause.

If you would like to participate in the tournament or to make a donation, please visit the website at www.coldwellbankergolf.com or call 415-762-2222.

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A New Approach to Treatment of Lysosomal Diseases of the Brain

Kristina Caffrey Four Years Later

Dear Friends,

Much has happened since I benched the first issue of this newsletter 4 years ago. Much has happened in the meantime. Kristina has started high school. She was healthy and happy.

The Cerazyme she took every 3 days turned her health around. The Cerazyme she took every 3 days was a breakthrough. The Cerazyme she took every 3 days was a lifesaver.

Kristina and I have been called to the hospital. We are on the way. A new treatment is available. A new treatment is available for this terrible disease. A new treatment is available for her.

The misfolded mutated glucocerebrosidase gene, which is the cause of Gaucher disease, is the cause of this disease. The misfolded mutated glucocerebrosidase gene is the cause of the disease. The misfolded mutated glucocerebrosidase gene is the cause of this disease.

The misfolded proteins (such as alpha-synuclein) are thought to cause Parkinson disease. The misfolded proteins (such as alpha-synuclein) are thought to cause Parkinson disease. The misfolded proteins (such as alpha-synuclein) are thought to cause Parkinson disease.

This is going to be an enormous scien
tific achievement. We don't know why Kristina is getting better. We don't know why Kristina is getting better. We don't know why Kristina is getting better.

A New Development

The size of the molecule used in the infusion process. But, whatever improvements are made, they are temporary. Kristina will be required to have the drug. Maybe it can be altered to give her protection for a longer time.

The misfolded glucocerebrosidase gene (the enzyme that is present but does not work) is the cause of Gaucher disease. The misfolded glucocerebrosidase gene (the enzyme that is present but does not work) is the cause of Gaucher disease. The misfolded glucocerebrosidase gene (the enzyme that is present but does not work) is the cause of Gaucher disease.

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When the Children’s Gaucher Research Fund began we had a simple goal: to find a cure for a rare orphan disease known as Gaucher disease (Type 2 and Type 3). With the help of our volunteers and donors we began funding research to find that cure.

In 2002 we began funding research in 2002 with Dr. Tony Futerman at the Weizmann Institute of Science in Israel. Dr. Futerman’s research was extremely important and was discussed in the September 2005 issue of a major medical journal: Nature Review/Neuroscience. Dr. Futerman asked that the cusp of pursuing this class of brain disorders. Our Research Funded research. The results of this research were extremely important and although earlier than we had anticipated, we read this article and said, “Note the section on calcium. The research was conducted on the brain as it relates to Neuronopathic Gaucher disease. Our research funding targeted medical research that would begin to pave the way.

In 2004 the CGRF in collaboration with the National Institutes of Health and the National Heart Lung and Blood Institute funded research at the University of California, San Francisco. This funding targeted medical research that would begin to pave the way for future research.

In 2005 the CGRF has come a long way. But it looks like we have reached the end of the road. The long-term research. Sometimes we are at a low point where we think that we have reached the end of the road. But as we look upon the faces of the children we are faced with passion. Countless individuals have offered their time, their talents and their hard-earned dollars. You are a collection of compassionate and generous people – people who have joined hands with these little faces to push beyond tragedy, and find a cure.

We find ourselves today in a position to make a difference for beyond our initial aspirations, we are bold, and it is exciting. We are financially preparing for the future, but very important. We are at a crossroads. We have reached the end of the road. But as we look upon the faces of the children we are faced with passion. Countless individuals have offered their time, their talents and their hard-earned dollars. You are a collection of compassionate and generous people – people who have joined hands with these little faces to push beyond tragedy, and find a cure.

Together, this journey will give life to thousands of children, for generations to come. However, great accomplishments can also be met with great challenges. The path has been long and difficult, but we are here to stay. The children whose lives have been curtailed by a caprice of nature, yet whose smiles give us hope at the future.

To those children whose lives have been curtailed by a caprice of nature, yet whose smiles give us hope at the future.
Vlade & Ana Divac – “A Diamond In The Rough”

Private Dinner

Anne speaks from her heart and captures the crowd.” – “A Diamond In The Rough”

Our fourteen guests gathered the evening of July 21st annually, awaiting the arrival of Vlade and Ana. I had the pleasure of working with Ana in the months leading up to these events and found her genuine, real people who help with so many charities. It has always been said that they really do care. When you meet these two people you quickly realize that there are no limits on autographs – and there was no limit on the time and talent that they could relax put everyone at ease.

The Divac’s generosity extended in our restaurant, 1. Unbeatable was the outcome located in the Palmer shopping center in Kansas City. Vlade and Ana have personally located 10 “cubicle guests” as private dinner and a celebrity celebration party held yearly.

Celebration Party

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Children’s Gaucher Research Fund

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In 2004 the CGRF in collaboration with the National Institutes of Health held a medical conference in Bethesda, Maryland. The goal of this conference was quite simple; to find a cure for Gaucher disease. With the help of funding targeted medical research that would begin to pave the way toward a cure.

Return Service Requested

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