My name is Cari Yang, the President of Florin High Key Club for the 2008-2009 academic year. I first joined Key Club my freshmen year, and was inspired to join because of my sisters and brothers - dedicated members of the club during their high school years. I learned that by volunteering, one can make a difference, and that people working together can make a bigger difference. My Key Club experience was one of my more important personal experiences. It taught me among other things, my first selfless service - volunteering.

In early 2002, I was asked to put together a charity golf tournament for Coldwell Banker as part of philanthropic community efforts with all proceeds benefiting a local charity. Our sister offices had a fun day golfing for a great cause! It’s June 24th, and my feet are killing me; not only that but my head is still spinning from yesterday’s non-stop activity directing the tournament; not only for the excitement, but also because I got to witness selfless generosity of others. The event is running like a well-oiled machine, but it couldn’t be so without a troop of individuals - some new faces as well as some familiar, committed and dedicated to our cause. One of the most popular of our corporate sponsors is Key Club, a national service organization whose main focus is selfless service to others.

Although this began as a work project, now it has grown to something bigger, something to which I look forward to each year, to become more than “work,” after I got to know Greg and other families has ushered in an extraordinary momentum that will continue year after year and with more and more people who will continue to advance this event for the betterment of our cause.

In the beginning of the goal of the CGRF was to find a cure for Gaucher Disease. This has now expanded to, “Combined, the prevalence of these diseases is 1:6000, a greater prevalence than Cystic Fibrosis and Muscular Dystrophy.” The CGRF has found a way continuously among all monophasic neuronopathic diseases that is not only life changing in young children, but it is also an area of hope for many children with Gaucher disease. Our CGRF has found a strong commonality among all neuronopathic diseases. Our quest is now to find a cure for all these diseases. Our CGRF has found a strong commonality among all neuronopathic diseases. Our quest is now to find a cure for all these diseases.

For more information please visit the website at: research@childrensgaucher.org

It should be noted that these conferences, as important as they are, are not funded by your donations. Funds to support these conferences are derived from companies who have an interest in supporting and attending these conferences. If you require information for a conference please contact the conference coordinator for some other source of financial support for the meetings.

I want to thank you for the opportunity to participate in the wonderful conferences. The next three conferences will take place in

2008 - Greg and Deborah black are the beacons. The following are the dates for the next three conferences. The information has been sent to you via email.

Dear Greg and Deborah,

We are excited to tell you the news of the upcoming conferences. The next three conferences will take place in 2008.

The first will be held in May 2008, and the second will be held in September 2008.

The third will be held in November 2008.

We are excited to see you at the conferences.

Sincerely,

Carol Black
President
By Raphael Schiffmann M.D.

The Lysosomal Diseases and the Brain Conference held in Sacramento in May 2008 was truly outstanding! All the participants truly believe the conference provided a superb discussion and highly stimulating forum and that much additional benefit was derived from one-on-one exchanges between participants. All strongly felt that the series most definitely should be continued.

The Lysosomal Diseases and the Brain series was established in the 1990's and continues to be a remarkable success story…

The recent ‘Lysosomal Diseases and the Brain’ conference in Sacramento was a superb occasion, containing in the present conference several features that were not extensively discussed was direct intracerebral injection of enzymes or gene therapy. The recent ‘Lysosomal Diseases and the Brain’ conference in Sacramento in May 2008 was truly outstanding! All the participants truly believe the conference provided a superb discussion and highly stimulating forum and that much additional benefit was derived from one-on-one exchanges between participants. All strongly felt that the series most definitely should be continued.

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Lysosomal Diseases and the Brain

The Lysosomal Diseases and the Brain Conference was the first of its kind. It was so well attended that the organizers were not sure if it would be successful. Now, the conference is well established and continues to attract the top researchers in the field of lysosomal disorders. The conference continues to be a remarkable success story..."  

Potential Therapies

The Lysosomal Disease and the Brain Conference continues to be a remarkable success story..."  

Potentially disease and Parkinsonism

The Lysosomal Disease and the Brain Conference continues to be a remarkable success story..."  

Important of the conference

The recent Lysosomal Disease and the Brain Conference in Sacramento was a spectacular success, combining, as in the previous conference, basic and clinical approaches. The biennial conference attempted to address were:

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Sacramento, California

CGRF was the strongest yet especially in terms of the basic science. Basic were able to assemble the top researchers in fields related to lysosomal disease for the devastating neurological complications of the lysosomal diseases. By Raphael Schiffmann M.D.

Therefore, our conference this year demonstrated through excellent discussions on an annual basis. We are happy to be on the list to contribute to your foundation.

Another important theme this year was the importance of ending the silent years that many lysosomal disease researches have spent in the drug trials field. The many breakthroughs in the area of treatment for neurological disorders and the need for a fresh approach led to

We would like to tell you about our daughter, Danielle. Let us introduce ourselves: we are Rick (dad) and Gloria (mom) Loncharich. We have been involved in the management of postnatal lesions since the initial report back in 1999. Our daughter, Danielle, was born with a rare congenital disease called Gaucher disease type 1.

In the 1999-2001 time frame, genetic and clinicopathologic descriptions of Gaucher disease and Parkinsonism (the enzyme affected in Gaucher disease) by "chaperones" (chemical molecules to block the formation of accumulating materials appears to offer a cure for these diseases) have been presented by Dr. Seng Cheng.

"In addition to Gaucher disease, more than 20 additional metabolic studies have been performed for CNS disorders..." - Tony Futerman Ph.D.

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**Florin High School Students**

**Raise $50 over $6 in 5 Years**

By the time I came to Florin High School, I had already been living with Gaucher disease for seven years. I had become used to managing my disease by taking my medications, receiving my enzyme replacement therapy, and attending all of my medical appointments. I was thankful for my family and the support of my doctors, and I was ready to move on with my life.

However, when I found out about the Gaucher Research Fund, I was blown away! I realized that there was a way that I could make a difference in the lives of others. I decided to join the Key Club at Florin High School and work with them to raise money for the Gaucher Research Fund. I knew that I could make a difference by using my voice to raise awareness and fund research.

It started with a small amount of money, but over the years, the Key Club at Florin High School has raised more than $13,000 dollars for the Children’s Gaucher Research Fund. This money will be used to fund research and support children who are affected by Gaucher disease.

I want to thank everyone who has supported the Key Club at Florin High School and the Gaucher Research Fund. Together, we can make a difference in the lives of those affected by Gaucher disease. Let’s continue to work together to make a difference in the world.

Carol Black

**Selfless Devotion**

**Children’s Gaucher Research Fund**

**Our daughter - a gift from God who will be eternally treasured**

I want to thank you for the opportunity to participate in the research conferences, the science and the bold vision of the investigators privileged to be part of this wonderful way to honor Gregory and all the extraordinary children who have suffered from these conditions. I am forever grateful for the dedication and tireless efforts of the researchers and the dedicated volunteers and generous sponsors, most of whom return in support and attend each conference. I hope that you will continue to support the research for a cure of neuronopathic lysosomal diseases.

It should be noted that these conferences, as important as they are, cannot be held without the support of our friends, families, and dedicated volunteers. These conferences are funded from companies who have an interest in supporting and attending these conferences. If you are interested in supporting the conferences, please contact the Children’s Gaucher Research Fund at 916 797 3707 or at research@childrensgaucher.org.
Florin High School Students
Raise $50,000 in 6 Years

Selfless Devotion
Florin High School Students
Mr. Elias Mendoza, Advisor
Florin High Key Club, Division 7
Cari Yang, President 08-09

opportunities that are not offered to teenagers anywhere else. The club provides me with the

serve with spirit!

surpassed our previous club record my raising more than $13,000 dollars for the Children’s

viewing the background of the Children’s Gaucher Research Fund,

in the Silicon Valley have been also coordinating their own golf

an enlightening and exhausting experience! Yet with 144 golfers

Deborah and their family personally. I can’t imagine how difficult

of Gaucher disease is the reason that our tournament committee

second of time that I spend coordinating a fundraising event or

strives to make each event better than the last. I’m honored to be

Wells Fargo Supports the CGRF

Resident (please see the Discussion in the Summer, 2008 newsletter the Scientific Advisory Board for the CGRF) presented research proposals. Three
dollars were approved and sent to peer review by

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Our club has been

Gregor in the Silicon Valley who became part of our tournament committee, has been

Golf Tournament. The last several months

not only that but my head is still spinning

from yesterday’s non-stop activity directing

It’s June 24th, and my feet are killing me;

and was inspired to join because of my sisters and brothers - dedicated

munity made me realize that I could do the same. Our club has been

is not rare, but common amongst my peers, because I see their selfless

working together can make a bigger difference. My Key Club experience

volunteering, an individual can make a difference, and that people

It’s shocking to realize that this was

thought that someday there WILL be a cure and knowing that our

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In the beginning of the goal of the CGRF was to find a cure for Gaucher disease. In 1993, the CGRF was established and

was the case in May, 2008, the closure of the conference averaged $4500, with

when it comes to effective treatments.

I wanted to thank you for the opportunity to participate in this wonderful

Conference: Greg and Deborah Macres pay the difference. The following

combined, the prevalence of these diseases

perfect transparency, we would be able to carry out our mission.

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In Loving Memory of

Wells Fargo supports the CGRF.

Refrain from: (www.lysosomal-brain-conf.org) attracted 126 scientific researchers

Lysosomal Diseases and the Brain

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Chief, Section of Pediatric Hepatology,

It is now believed that a cure for one will lead to a cure for all.

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Inside this Issue...

Gaynor Soy, Ph.D.

Wong A. Mok, Ph.D., F.R.C.P.

Professor of Pediatrics and Child Health, Chief, Section of Pediatric Hepatology,

Yale University School of Medicine

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3. We

www.childrensgaucher.org

100% of every donation

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