Summer 2004 HELPING HANDS

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

THE ONLY THING INCURABLE IS OUR PASSION.



Victoria Gregory Villar Austin Macres

Yannias

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DeFacci Dennis Tyler Cooper Doran Ir.

Rvan Lauren Marsh lames Conklin

Robert

Watson

Cameron Kristina Madeline Grant & Hannah Collin Geven

Garrett Colwell Pozzobor

ur Goal - The goal of the Children's Gaucher Research Fund is clear; to find a cure for Neuronopathic Gaucher disease. Our medical research focuses on the brain, because brain involvement is responsible for taking the lives of affected children. In the medical research community, the brain, more than any other organ in the body remains a mystery. With your support, we have funded two years of research with Dr. Tony Futerman at the Weizmann Institute of Science in Rehovot, Israel. We are making great progress.

Lysosomal Storage Diseases - It is important to understand that Gaucher disease is in a category of diseases called Lysosomal Storage Diseases (LSD). There are a large number of LSD's that affect the brains of young children (Gaucher

"With over 100 in attendance, medical researchers from around the world (Israel, United Kingdom, Italy, Switzerland. Canada, and across America) gathered in Bethesda, Maryland, to present, discuss, debate and collaborate."

- Tay-Sachs Niemann Pick Batten's Krabbe
- Sandhoff Mannosidosis Fucosidosis Sialidosis
- Mucolipidosis etc.) Individually, lysosomal diseases that affect the brain are rare, however collectively they affect 1:7000 births. Our challenge is to understand the mechanism of disease (on a molecular level, how the disease affects the brain) and to develop methods to deliver to the brain therapies that will prevent, and hopefully reverse brain dysfunction. Although each lysosomal

disease has a different etiology (the exact factors that cause the disease), it is likely that common pathogenic processes exist (cellular events and reactions that cause problems). Therefore, advances in one lysosomal disease will likely benefit, and potentially lead to a cure for the other lysosomal diseases mentioned above.

We Had An Idea - In August of 2003 we had an idea. Bring together the best in the world, those who are researching brain disease for all of the lysosomal diseases. Create an environment whereby ideas will cross-pollinate, research will be shared, and collaborations will be fostered. You are probably surprised, as we were, that this had not been done before. A Scientific Conference that is pure (100%) scientific presentations, strictly focusing on brain dysfunction in lysosomal diseases,

representing the best and the brightest who openly share cutting-edge research. As the conference notices were mailed in January 2004, there was no way to predict the response we would receive from the

medical research community. It was overwhelming! On two occasions, in preparation for the conference, it was necessary to increase the size of the conference room at the Bethesda Marriott Hotel.

Conference: Lysosomal Diseases and the Brain - On May 14 and 15, 2004, the Children's Gaucher Research Fund joined hands with the most

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Gregory Macres Chairman/Founder



Deborah Macres R.N. Founder

prestigious medical institution in the world, the National Institutes of Health. Together, we hosted a one-of-a-kind medical conference titled "Lysosomal Diseases and the Brain". Two full days of pure medical research. With over 100 in attendance, medical researchers from around the world (Israel, United Kingdom, Italy, Switzerland. Canada, and across America) gathered in Bethesda, Maryland, to present, discuss, debate and collaborate. Presented, was the most recent "cutting-edge" medical research. In this newsletter Dr. Raphael Schiffmann from the National Institutes of Health, will summarize the conference, and describe the importance of this unique event.

Thank You - We would like to take this opportunity to thank you. Those of you reading this newsletter gave birth to this research fund. Your support has funded research that is in the process of determining the exact cause, on a molecular level, of neuronal death in the brain. In addition, your research is determining the exact locations of the brain that are affected and correlating these locations with clinical symptoms displayed by children. Equally important, your support has fostered respect within the medical community. Families – Donors – Volunteers - You are now instrumental in bringing the medical research community together in a common effort to find a cure. A cure, not only for Neuronopathic Gaucher disease, but also for a host of lysosomal diseases that affect children. With utmost sincerity, and a humble heart, we thank you for your continued support.

You are accomplishing more than you know.

Mikkey Timmer - Our Little Princess - Page 4

"Many times a day I realize how much my own outer and inner life is built upon the labors of my fellow men, both living and dead, and how earnestly I must exert myself in order to give in return as much as I have received."- Albert Einstein

"Lysosomal Diseases and the Brain" Conference Summary



Let me begin by saying that the Children's Gaucher Research Fund, its supporters, and its volunteers are to be commended for the progress you have made. You are raising funds, applying 100% of those funds to research (novel and commendable by itself), and you are funding important research that has already provided important new discoveries. In addition, you have provided the leadership to narrow the focus to an important area of medicine; "Lysosomal Diseases and the Brain."

On May 14th and 15th, 2004, we had the first conference titled "Lysosomal Diseases and the Brain". The conference was impressive in terms of material presented, and the conference was impeccably organized. Over 100 scientists and health professionals came from across the United States and various other countries to attend lectures from top experts in the field of basic science and translational science of lysosomal diseases and related topics. The conference was unique of its kind because it brought together for the first time a variety of basic scientists interested in the neurological and neuroscience aspects of lysosomal diseases.

THE CALCIUM CONNECTION

The conference began with a presentation by Dr. Tony H. Futerman from the Weizmann Institute in Rehovot, Israel. He described his groundbreaking work on the mechanism by which the glycolipids, that accumulate in Iysosomal disorders such as Gaucher disease, Sandhoff disease and Niemann-Pick disease, perturb the function of nerve cells. Thus far, he found that in each channel, calcium pump or synthetic enzyme. This work, <u>supported by the first grant of the</u> <u>Children's Gaucher Research Fund</u>, is critical to explain the consequences of these enzyme deficiencies and may also open avenues for novel therapies. The importance of this work also lies in the fact that although these neurological diseases are called 'lysosomal', the material that is not broken down in sufficient amounts causes harm in extra-lysosomal regions of the cell. This led Professor Gregory Grabowski to make the statement that, "The concept of the lipid just sitting in the cell...is gone".

CALCIUM CONNECTION SUPPORTED

Dr. Kondi Wong, a neuropathologist from the Wilford Hall Medical Center in Texas, described his extensive and comprehensive study of the neuropathology of patients with Gaucher disease. Dr. Wong found a characteristic pattern of abnormalities in all types of Gaucher disease that varied only in severity. The selective vulnerability of nerve cells or areas in the brain of Gaucher patients are rich in calcium channels or receptors that were found by Dr. Futerman to be the most susceptible to the accumulating glycolipids in Gaucher disease. Thus, the biochemical abnormalities seem to fit nicely with actual neuropathological changes that are seen in patients with Gaucher disease.

BIOCHEMICAL CONSEQUENCES

Dr. Steven U. Walkley from the Albert Einstein College of Medicine in New York further discussed the changes in neuronal structure (and probably in function) that are caused by the

"This work, supported by the first grant of the Children's Gaucher Research Fund, is critical to explain the consequences of these enzyme deficiencies and may also open avenues for novel therapies."

case the presumed "offending metabolite" causes abnormalities of ionized calcium (Ca²⁺) signaling in the cell and also seem to activate important enzymes in the cell. In accordance with the variable neurological and neuropathological abnormalities in each of these disorders, Dr. Futerman found that in each of these diseases, the stored material affects the function of a different calcium

accumulating glycolipids in a number of lysosomal diseases. Of particular importance are the additional number of neuronal cell extensions called dendrites that are caused by the accumulating lipid GM2 ganglioside. This material accumulates in a number of lysosomal diseases, and in each case the same structural abnormalities of nerve cells occur. In a healthy brain, GM2 ganglioside is



Conference Speakers.

present mostly in the immature stage and very little in the mature brain. Therefore, when this material accumulates it affects the development of neurons. One of Dr. Walkley's main findings was that cholesterol accumulates in the nerve cells in many of these diseases and its extent depends on the storage of GM2 and GM3 gangliosides, showing, that in addition to distinct mechanisms, there are also biochemical consequences that are present in a number of these diseases.

INFLAMMATORY MECHANISMS

Dr. Richard Proia from the Genetics of Development and Disease Branch, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health in Bethesda, Maryland, demonstrated the importance of inflammatory mechanisms in a number of lysosomal disorders. Therapeutic actions, such as bone marrow transplantation, work by decreasing the inflammatory response and as a result there is a very significant improvement in the health and longevity of animal models for these diseases.

ANIMAL MODELS

Dr. Edward Schuchman from Mount Sinai School of Medicine in New York showed how critical the animal models are for the development of new therapies for these diseases. His mouse model for Niemann-Pick disease faithfully reproduced the human disease and allowed him to study the physiological abnormalities in this disease. In addition, he developed very promising enzyme replacement, bone marrow, and gene therapies for these diseases. His work also uncovered possible fundamental obstacles in these forms of therapies such as the development of antibodies to the infused enzyme or transplanted cells, and the abnormal cellular trafficking of receptors that are critical for the uptake of therapeutic enzymes into diseased cells.

"The conference was a gathering of up to date research from many fields of study ... Where there was once limited vision and insight, now, more than a glimmer of hope, we have the fundamental building blocks of understanding and conceptual maps for research and development toward treatment and cure."

-Lt. Col. Kondi Wong M.D. USAF MC - Wilford Hall Medical Center; Lackland, AFB Texas



Dr. Charles H.Vite, a veterinarian from the University of Pennsylvania, uses large animal models of lysosomal diseases to test different forms of gene transfer into the brain. Dr. David A. Wenger, from Jefferson Medical College in Philadelphia, studies Krabbé disease in small and large animal models. He successfully prolongs the life and improves the neurological status of affected mice using bone marrow transplantation and gene therapy approaches. He notes that mice end up dying despite correction of important biochemical imbalances. His work further demonstrates the need to better understand the mechanism of disease and the way various therapeutic approaches affect the diseased brain.

SUBSTRATE REDUCTION THERAPY

Dr. Fran Platt from the University of Oxford, in England, demonstrated the feasibility of substrate reduction therapy in treating lysosomal diseases of the brain. Animal models and human studies seem to prove the concept of using small molecules that decrease the production in the brain of the lipids that accumulate in lysosomal diseases. Dr. Platt stressed the potential of combining substrate reduction with medications that decrease the inflammatory response in the brain. Professor Ari Zimran from the Shaare Zedek Medical Center in Jerusalem, Israel, described the therapeutic effects as well as the undesired effects of miglustat (Zaveska - a substrate reduction therapy) in the treatment of patients with non-neuronopathic (type 1) Gaucher disease. The results of these studies provide the rational for ongoing clinical trials in a variety of lysosomal diseases using this compound.

CHEMICAL CHAPERONES

Dr. Jian-Qiang Fan, of Amicus Therapeutics, Inc., described a very interesting novel therapeutic approach that may be applicable to many lysosomal disorders. Some small molecules that are termed chemical chaperones, are able to increase the activity of deficient enzymes. They do this by binding to the active site of the mutated enzyme and normalizing its structure allowing it to enter the lysosome, its correct location in the cell. In this appropriate environment the affected enzyme can work better and significantly decrease storage. This approach is soon to be tested in humans.

NEURONOPATHIC MOUSE MODELS

Professor Gregory Grabowski described his extensive development of mouse models for Gaucher disease. This venture was proven very difficult, in particular, the generation of a mouse model for neuronopathic Gaucher disease. Since complete absence of affected enzyme is not compatible with life, various mutant mice with human mutations were generated but none provided a neuronopathic model, although, some reproduced moderately well the extra-neurologic aspects of the disease. Two mice models that combine the primary enzyme deficiency with a

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deficiency of another protein that activates the enzyme that is deficient in Gaucher disease did develop a neurological disorder. However, it is not clear if this is an appropriate representation of brain abnormalities of Gaucher disease. Dr. Grabowski also briefly reported on the genomics study that provided the secondary gene and protein changes in these mouse models. This information may be important to better understand the mechanism of damage in Gaucher disease or to follow the effect of specific therapies.

BLOOD-BRAIN BARRIER

A major obstacle to the delivery of therapeutic genes and proteins to the diseased brain is the presence of the blood-brain barrier. Dr. David Begley from Kings College in London, England described the function and characteristics of this barrier and the potential ways by which it can be circumvented. Dr. William Pardridge from the University of California in Los Angeles further defined the type of small molecules that better cross the blood-brain barrier. He described a series of promising approaches to deliver large proteins or genes to the entire brain by using fatty particles that are coated by antibodies to receptors on the surface of the blood vessels in the brain. Dr. Thomas Jacobs of the National



Institute of Neurological Disorders and Stroke at Bethesda, Maryland presented the Institute's initiative to fund studies on the blood-brain barrier. There is a general agreement that such work is crucial for the ultimate cure of the neurological manifestations of lysosomal diseases and others.

CONFERENCE CONCLUSION

We can conclude from the conference that progress in lysosomal disorders will likely help other diseases of the same class. In addition, it seems clear that one has to work simultaneously on the mechanisms of these diseases and on the

> development of novel therapeutic approaches. Appropriate animal models are very important for all these studies. Some diseases have adequate animals models, but others, such as neuronopathic Gaucher disease, do not. Finally, promising therapeutic agents exist but adequate means for delivering them throughout the brain have yet to be to be developed. The latter constitutes a major hin-

drance to the successful development of novel therapies in lysosomal diseases of the brain.

RESEARCH BRINGS HOPE

Advances in medical science always take longer than we wish. As recent as five years ago this article I have written would have taken significantly less time, and would have startled you with its brevity. Five years ago, much of the research discussed above did not exist. Today, we have medical researchers pursuing a variety of therapeutic interventions. There is more hope for these children today, than at any time in the past. I will conclude by again commending and thanking the fund, its donors and its volunteers for their incredible work. I will borrow a line from the first article in this newsletter:

"You are accomplishing more than you know."

RAPHAEL SCHIFFMANN M.D. Lead Investigator

Lead Devel Neuro Natio Disoro Natio

Lead Investigator Developmental and Metabolic Neurology Branch National Institute of Neurological Disorders and Stroke National Institutes of Health Bethesda, Maryland

"The conference was a total success ... I have waited a long time for this topic to become centre stage and as a parent it sends shivers down my spine and brought a tear to my eyes listening to all of the wonderful people that one day will make such a difference to many people's lives." -Tanya Collin-Histed - UK Niemann Pick Disease Group, England



Speaker List

David Begley Ph.D.

Centre for Neuroscience Research Kings College, London "The Blood-Brain Barrier: Delivery of Therapeutics to the CNS, the Problems and the Possibilities."

Jian-Qiang Fan, Ph.D.

Amicus Therapeutics, Inc. "Active-site Specific Chaperone Therapy: Implications in Lysosomal Storage Disorders."

Tony Futerman Ph.D.

Weizmann Institute of Science - Rehovot, Israel "Pathophysiology of type 2/3 Gaucher Disease."

Greg Grabowski M.D.

Children's Hospital Research Foundation of Cincinnati "Animal Models and Pathogenesis of Gaucher Disease."

Pedro Huertas, M.D.

StemCells, Inc., Palo Alto, CA "The Use of Human Central Nervous System Stem Cells (hCNS-SC) to Treat Infantile Neuronal Ceroid Lipofucinosis."

Olivier Morand, Ph.D.

Actelion Pharmaceuticals Gewerberstrasse, Switzerland "New Horizons for SRT in Glycosphingolipid Storage Diseases."

William Pardridge M.D.

University of California at Los Angeles "Intravenous, Non-viral Gene Therapy of the Brain."

Fran Platt Ph.D.

University of Oxford - UK "Substrate Reduction Therapy."

Richard Proia Ph.D.

National Institutes of Health "Role of Inflammation in the Neurodegeneration of Sandhoff Disease."

Edward Schuchman Ph.D.

Mount Sinai School of Medicine - New York "The Use of Bone Marrow-Derived Cells for the Treatment of Brain Disease in a Mouse Model of Niemann-Pick Disease."

Greg Stewart Ph.D.

Genzyme, Corporation, Framingham, MA "Gene or Cell Based Enzyme Replacement Therapy Leads to Widespread Correction of Storage Pathology in a Mouse Model of Niemann Pick A Disease."

Steven U. Walkley D.V.M. Ph.D.

Albert Einstein College of Medicine - New York "Secondary Glycolipid Accumulation in Lysosomal Disorders."

David A. Wenger Ph.D.

Jefferson Medical College- Philadelphia, PA "Treatment Approaches for the Mouse Models of Globoid Cell Leukodystrophy"

Lt. Col. Kondi Wong M.D. USAF MC

Wilford Hall Medical Center, Lackland Airforce Base, TX "Neuropathology of Gaucher Disease: Calcarine Cortex Layer 4B and Hippocampal CA4-2 Region Pathology with Synuclein Positive, Lewy Body-like Inclusions."

Charles H.Vite, DVM, PhD

School of Veterinary Medicine University of Pennsylvania "Adeno-Associated Virus Vector-Mediated Gene Transfer to the Brain of Cats with Alpha-Mannosidosis."

Ari Zimran M.D.

Shaare Zedek Medical Center - Jerusalem, Israel "Zavesca®" in Adult Patients with type I Gaucher Disease - Implications for Use in Neuronopathic Forms."



This is the story of our little princess Mikkey Wilhelmina Aaltje Timmer; we called her Mikkey. On June 11th, 1999 our little girl Mikkey was born. I had a wonderful pregnancy. Mikkey was our first child. She weighed 2500 grams. Small and beautiful; we were delighted with our new bundle of joy.

We live in a small town in The Netherlands and here is where we were looking forward to creating and caring for our growing family. At this point we were in love with our new

Mikkey Wilhelmina Aaltje Timmer

Our Little Princess

daughter, excited for the future, had not heard of a disease called Gaucher, and had not yet been introduced to the Children's Gaucher Research Fund.

I nursed Mikkey for a couple of months but she didn't grow enough so I supplemented with a bottle. When she was four-months-old she had a cold - we thought. She started coughing a bit and I brought her to the doctor. He thought that she had bronchitis and he gave us some Penicillin. After a few weeks she was still coughing and had a fever. She also had very little red/brown spots on her face and on her chest. We returned to the doctor and he was perplexed. He said that she was probably a sensitive girl who could easily get a cold. After 5 visits to various doctors we requested a visit with the children's clinic in the hospital.

Our little princess was still coughing, and we could hear her breathing. The

only thing she would eat was milk, and she began to lose weight. Mikkey also started crossing her eyes. Three days after our visit to the children's clinic we were rushed by ambulance to the hospital. Mikkey had severe breathing problems. After a couple of weeks in the hospital she was diagnosed with influenza. We were so relieved. She had a virus that would eventually disappear. From that moment on we began to feed her through a sonde in her nose. The doctors told us that she needed time to get better. They also thought that our little princess had a narrow airway that could be the reason for her breathing problems. To be sure it was necessary that the doctors do a bronchoscopie. If a narrow airway was the cause of her problems the only cure for Mikkey was to grow out of it. The bronchoscopie would be performed in a larger hospital in another town.

It was the end of February 2000. Just prior to her bronchoscopie, Mikkey again had severe breathing problems. Immediately, there were doctors and nurses surrounding us. One of the doctors who observed said that she believed that there was something very wrong. They cancelled the bronchoscopie and immediately transferred Mikkey from the medium care to the special care unit. The doctors had no idea where to look so they started to examine everything. Mikkey was 7-months-old. Although she had been sick for 3.5 months she was a very happy baby who loved to laugh. She reacted so beautifully to all the songs we sang for her. We loved her deeply. We stayed in the hospital day and night. We were so frightened.

After ten days in the hospital, on March 7th, 2000, Mikkey was diagnosed with Gaucher disease Type 2. Our world collapsed. Our precious

-continued from page 4

baby was going to die? The doctors were very clear, there was no cure. We were told our daughter would probably die before she was 2-yearsold. Her liver and her spleen were already enlarged. Eventually, brain dysfunction would cause her death. We wanted to know in which stadium Mikkey's disease was and how long we could still enjoy her. But the doctors could not give us answers. They had no idea. We cried every day.

Mikkey had breathing problems 2 or 3 times a week. We had to suction her mouth and her throat

often and everybody fell in love with her. She was so special. She was our "Everything".

Two weeks after her diagnosis we took Mikkey home. The nurses in the hospital had coached us so we could perform all of the necessary treatments. We had four tanks of oxygen, medicine, a machine to suction her throat, and a feeding pump. We loved being at home. We played with her, we sang for her, and we gave her all the love and affection we could give. In return, she gave back all the love she could give. These days wanted to do so much with her. We wanted to go to the zoo. We never got there.

Exactly two weeks after Mikkey returned home she had severe breathing problems. It was terrifying. In the hospital the trauma team put a tube in Mikkey's throat and the machine took care of her breathing. At that moment, for the first time, we realised that Mikkey was extremely ill. Because she was so cheerful and happy and because she still laughed so much we hoped that her sickness was in its first stadium. At this time

we knew that that this was not the case. After a few days the doctors removed the breathing tube. Remarkably, Mikkey recovered. Our little girl, our fighter had done it again! However, we noticed

that she was less enthusiastic; she had suffered so much. We felt incredible compassion for her. We loved her so much! Mikkey went from intensive care to special care and step-by-step she got better. We were waiting on the moment that we could go home.

Three days later, on April 26th, 2000, the doctors woke us up at 4:45 in the morning. Mikkey was not doing well. She had very severe breathing problems. The doctor told me to put Mikkey on my lap. We could not make contact with her. Her eyes were closed and she was in a terrifying situation. She had a very high fever and she needed oxygen. We were so scared. The entire day we held her on our laps. She was so sick. The fever became worse and she seemed to be in a coma. We sang to her, talked to her, thanked her and said goodbye to her. The next night, at 1:15 a.m., Mikkey died in our arms. She had given all she had, but she could not win the battle. Our little princess. The love of our life.

Seven weeks after we heard about this terrible disease our daughter died. Mikkey was ten months and sixteen days old. Mikkey Wilhelmina Aaltje Timmer. That was her name. For always written in our thoughts and in our hearts.

Geert Jan Timmer Alexia Timmer-Oostland The Netherlands

"She had given all she had, but she could not win the battle. Our little princess. The love of our life."

with a machine and we gave her extra oxygen when she needed it. She received medicine, some oil to grow, and antibiotics because she was susceptible to infections. When she didn't have the breathing problems she was a very happy girl. She laughed were very intense. We knew that we had to cherish every moment we had with her. And we did. Two times we went for a drive. GeertJan was in the backseat next to Mikkey with all the equipment in case of emergency. I drove. There was one thing we

Charity Golf Tournament



June 21, 2004 marked the Third Annual Coldwell Banker Charity Golf Tournament benefiting the Children's Gaucher Research Fund, held at Valley Hi Country Club in Elk Grove. Nearly 200 golfers, volunteers, lunch and dinner guests were on hand to participated in this worthy charity event, beginning with a barbeque lunch and putting contest, 18 holes of golf, cocktails and dinner and capped off by a live auction. Coldwell Banker is still tallying all of the money raised for the Fund, but it appears that is will closely match previous years donation - just the live auction, prize raffle and 50/50 Cash raffle, they raised \$10,500!

The winner of the 50/50 Cash Raffle was Doreen Holden, wife of volunteer Auctioneer and Coldwell Banker Folsom Lake office Sales Associate Stephen Holden, who won \$1,485.

The support from all of the Coldwell Banker offices selling raffle tickets was amazing- nearly \$3,700 was raised in the offices alone- Maxine Feil and Sher Granata from the Roseville Granite Bay office raised the most money as an office with \$1,140. They will receive a catered brunch at an upcoming July office meeting and one month of banner advertising on Sacbee.com for their efforts- congratulations and thank you!



100% To Research

It is important that you know that your donations did not pay for any part of the Scientific Conference. Corporate sponsors who have an interest in brain research sponsored the conference, "Lysosomal Diseases and the Brain" that took place on May 14 and 15th, 2004. We continue to maintain our commitment – If you send your hard earned dollars – It <u>ALL goes to medical research</u>.

"It was a thoughtful conference with an impressive percentage of the world's top scholars ... Next time you run it, we at TKT will have interesting new data on MPS."

Mike Astrue - President and CEO, Trankkaryotic Therapies, Inc.

Working Until Midnight

Carol Black-Wagonner

WOW! It wasn't enough that Carol has been the Chairman and "chief organizer" of the Coldwell



Banker Charity Golf Tournament for three years in a row. When she heard in August of 2003 that we were thinking of breaking new ground with the "Lysosomal Diseases and the Brain" conference she was the first to stand up and take charge. As the

conference coordinator; Carol was superb! As a nationally renown neuropathologist put it, "I have attended over 100 medical conferences ... this is the best one I have attended." Many hours – Working until midnight – Thank You Carol.

Visit our web siteat: 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

An Opportunity to Help

The Children's Gaucher Research Fund has signed up for a new fundraiser with a health and wellness company, where families can shop for better, cheaper and safer products for their households such as: toothpaste, laundry detergent, soap, shampoo, vitamins, and 300 other great products. Not only does your family benefit from these healthier, non-toxic products, but every time you shop, the Children's Gaucher Research Fund will receive 7% back from your order. This means that each month the Children's Gaucher Research Fund will receive a check simply from you and others like you shopping for your everyday consumables. Each month you will be bringing us closer and closer to a cure.

In addition to the option of joining this fundraiser as a customer and shopping for your everyday household products, this company also offers a work-from-home business opportunity. If you are interested in joining as a customer or if you would like more information about the home business opportunity, please e-mail Suzy Ashley at sashley2@cfl.rr.com or go directly to the workfrom-home website http://suzy.internetmoms.net and fill out a request form.

United Way And You

Many of you probably participate in a United Way program at work or in your community. Did you know that United Way allows you to designate your favorite charity to receive your United Way contribution? Please remember this when you fill out a pledge, as the Children's Gaucher Research Fund is a fully eligible 501c3 charity.

Children's Gaucher Research Fund



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