**Charity Golf Tournament**

The Charity Golf Tournament was a successful event where Geert Jan Timmer, a doctor, and his wife, Geert Jan Timmer, a nurse, organized a golf tournament to raise funds for a charity. The tournament included golf, cocktails, and dinner, and ended with a raffle. The proceeds from the event were donated to the Children’s Gaucher Research Fund. The event was well-attended, and the organizers were very pleased with the outcome.

**United Way And You**

United Way is a global movement that brings people together to advance the common good. They work to create long-term solutions that address the most pressing community needs, support education, and promote financial stability. By donating to United Way, individuals can make a difference in the lives of those in need. United Way’s mission is to help families thrive, and they achieve this through partnerships and collaborations with local organizations.

**An Opportunity to Help**

The Children’s Gaucher Research Fund is dedicated to finding a cure for Gaucher disease and other lysosomal storage diseases. They are working on a research project that involves cutting-edge techniques and new technologies. By donating to the Children’s Gaucher Research Fund, individuals can support important research that is making a difference in the lives of those affected by Gaucher disease.

**The ONLY THING INCURABLE IS OUR PASSION.**

Our mission is to understand the mechanism of disease on a molecular level, how the disease affects the brain, and to ultimately find a cure. Our research focuses on the brain, because brain dysfunction is a hallmark of diseases such as Gaucher disease.

**The General Committee**

The General Committee is responsible for planning and executing the conference. The committee includes representatives from various institutions, and they ensure that the conference runs smoothly. The committee is composed of dedicated professionals who work hard to ensure that the conference meets the needs of its participants.

**June 2004** marked the 10th Annual Golf Tournament benefiting the Children’s Gaucher Research Fund, Inc. (CGRF) and the Children’s Gaucher Research Fund, Inc. of Switzerland. The tournament was open to all who wished to participate and raise funds for the CGRF. The event was a huge success, and the organizers are looking forward to future tournaments.

**Summer 2004**

We are excited to announce that we have a new website, [www.childrensgaucher.org](http://www.childrensgaucher.org), where you can find information about our research, upcoming events, and how to get involved. We encourage you to visit our website to learn more about our mission and get involved in the fight against Gaucher disease.

**Contact Information**

For more information, please contact the Children’s Gaucher Research Fund, Inc. at 949-940-3818 or [info@childrensgaucher.org](mailto:info@childrensgaucher.org).

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**100% To Research**

In our ongoing research, we are committed to finding a cure for Gaucher disease. Your donation will help us achieve this goal and make a difference in the lives of those affected by Gaucher disease.

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**July 17, 2004**

We would like to express our gratitude to all of those who participated in the tournament and contributed to the success of the event. We are grateful to all of the sponsors who supported the event and made it possible.

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Lysosomal Diseases and the Brain

Conference Summary

Levine began by saying that the Children’s National Medical Center’s research in lysosomal diseases is vicarious for the children in the center while being therapeutic for all. While research in lysosomal diseases has been challenging and mercurial to date, he said that he is finding impetus and nourishment from the patients who are affected by lysosomal diseases. In addition, he said that he has grown restlessly familiar with the biology of lysosomal diseases in the past few years.

Dr. Richard Proia from the Genetics of Aging, Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Bethesda, Maryland, demonstrated the importance of inflammatory mechanisms in the development of lysosomal disorders. Dr. Proia started his remarks by identifying that the lysosome is a single cell organelle and that many lysosomal diseases result from the presence of autophagy, which occurs in a number of these diseases.

Inflammatory mechanisms play a critical role in the clearance of autophagy in many of these lysosomal diseases. The inflammatory mechanism is the best example of this, as it is a vascular, immune, and inflammatory reaction that is seen in other diseases of the same class. In addition, it demonstrates the need to better understand the inflammatory mechanisms of these diseases.

The conference was unique in its kind because it brought together for the first time a variety of basic scientists interested in the neurobiological and neurophysiological aspects of lysosomal diseases.

One of the main themes of the conference was the importance of identifying and understanding the mechanisms of these diseases, which are termed chemical chaperones, are able to do this by binding to the active site of the mutant enzyme and normalizing its structure allowing it to enter the lysosome, its correct location in the cell. The conference also featured presentations on the mechanisms of these diseases and on the potential for therapeutic interventions. There is more hope for ongoing clinical trials in a variety of lysosomal diseases than there has ever been before.

Life is too short to live mediocrately. What we could do is start thinking of doing things that will make a difference in the world. Life isn’t just about waking up to work, eating, and going to bed. It’s about making a difference. Life is more than just surviving; it’s about living.

The lyrics for the future held in music, Dr. William Pardridge from the University of Pennsylvania said. "The Blood-Brain Barrier: Delivery of Therapeutics to the Brain". The conference was in the form of a presentation by Dr. Tony Futerman from the Weizmann Institute of Science in Rehovot, Israel. He described his ground-breaking work with Gaucher disease.

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“Lysosomal Diseases and the Brain”

CONFERENCE SUMMARY

Let me begin by saying that the Children’s National Health System’s Lysosomal Diseases, National Institutes of Health, Bethesda, Maryland and here is where we developed a lysosomal disease and the triennial meeting was held.

The conference centered on the challenges and the challenges were the major focus of the meeting. The major problem of the meeting was how to improve the quality of life for these patients and their families. The meeting was a great opportunity to learn about the latest developments in the field and to interact with experts in the field. The meeting was also a great opportunity to meet other researchers and clinicians who share the same interest in the field of lysosomal diseases.

This year, the meeting was attended by nearly 200 attendees, including researchers, clinicians, and patients. The meeting featured keynote presentations, plenary sessions, and panel discussions on a wide range of topics related to lysosomal diseases.

The conference was unique because it brought together the first time for a basic understanding of the neurological and neuropsychological aspects of lysosomal diseases.

Furthermore, the conference included a special session on neurodegeneration in lysosomal diseases. This session featured talks from researchers who have made significant contributions to the understanding of the mechanisms of neurodegeneration in lysosomal diseases.

The conference also included a panel discussion on the future of lysosomal disease research. This panel featured experts from academia, industry, and government agencies who discussed the challenges and opportunities in the field of lysosomal disease research.

In addition to the scientific sessions, the conference also featured a patient workshop, where patients and their families had the opportunity to ask questions and share their experiences with the experts in the field.

Overall, the conference was a great success, and it provided an excellent opportunity for researchers, clinicians, and patients to come together and share their knowledge and experiences.

The conference was sponsored by the Children’s National Health System’s Lysosomal Diseases, National Institutes of Health, Bethesda, Maryland.

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The conference was unique of its kind as it brought together for the first time a variety of basic and clinical researchers interested in the neurological and neurocognitive aspects of lysosomal diseases.

Dr. Charles Hill, a veteran of the National Institute of Neurological Disorders and Stroke, opening the conference, described the importance of the lysosomal storage diseases and the need for multidisciplinary approaches to understand their complex pathogenesis. He emphasized the critical role of research in improving diagnostic tools and therapeutic strategies.

The conference featured presentations from top experts in the field of basic and clinical research on lysosomal diseases. The sessions were well-organized and covered a wide range of topics, from the molecular basis of these disorders to the latest therapeutic approaches.

Dr. Jian-Qiang Fan, of Amicus Therapeutics, Inc., discussed the potential of small molecules that decrease the production in the cell of the disease-causing enzyme. He described the results of clinical trials in patients with Gaucher disease and highlighted the challenges in developing effective treatments for this disorder.

Dr. William Pardridge from the University of California, Los Angeles, described his work on delivering therapeutic agents to the brain. He discussed the development of drug delivery systems that can cross the blood-brain barrier and the potential ways by which it can be circumvented. His team has been successful in delivering therapeutic agents to the brain in animal models.

Professor Gregory Grabowski described his initiative to fund studies on the blood-brain barrier. There is a general agreement that such work is critical for all these studies. Some breakthroughs are already visible in mouse models of lysosomal diseases to test different therapeutic approaches. Appropriate gene and gene therapy approaches are being explored, and one of the key questions is how to specifically correct the neurological changes that are present in a number of these diseases.

Dr. Charles H. Vite, a veterinarian from the Netherlands, described the importance of understanding the mechanisms that underlie the neurological changes seen in patients with lysosomal diseases. He emphasized the need for multidisciplinary approaches to address these complex disorders.

The conference also featured a presentation by Dr. Tony Futerman, who discussed his work on the blood-brain barrier. He described the development of new strategies to deliver therapeutic agents to the brain and highlighted the potential of using gene therapy to correct the neurological changes seen in patients with lysosomal diseases.

Dr. Richard Proia, from the National Institutes of Health, presented his work on the development of new therapeutic approaches for Niemann-Pick disease. He emphasized the importance of understanding the pathophysiology of these disorders to develop effective treatments.

The conference concluded with a panel discussion on the future of lysosomal disease research. The panelists discussed the need for continued investment in basic research and the potential of new technologies, such as gene therapy, to address these complex disorders. They emphasized the importance of multidisciplinary approaches and the need for international collaboration to advance our understanding of these disorders.

The conference was a total success and I have waited a long time for this topic to become centre stage and as a parent it sends shivers down my spine. Mikkey Wilhelmina Aaltje Timmer; we are the parents of a girl with Gaucher disease.

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The Charity Golf Tournament

June 2004 marked the best-ever Charity Golf Tournament benefiting the Children’s Gaucher Research Fund, held at the Roseville Granite Club in Granite Bay. Nearly 200 golfers, volunteers, auctioneers and Administrative Assistants combined forces to create an event that raised $15,000! All proceeds were used for a service called “la Casa Young at Heart.” The primary purpose of this fund is to provide care to special needs children in the area by offering services and supplies to their families in case of an emergency. There are many other strong and wonderful children who are ready to give in love and work.
Charity Golf Tournament

The Children’s Gaucher Research Fund was proud to host the Charity Golf Tournament to raise funds for research into Gaucher disease and microscopic storage diseases. The event was held at the beautiful Sierra Nevada Golf Club in Lake Tahoe, California. Participants enjoyed a day of golf, food, and friendly competition in support of Gaucher disease research.

Thank you to all of our golfers, sponsors, and volunteers for making this event a success. Your support makes a difference in the lives of those affected by Gaucher disease.

Get involved today! Visit www.childrensgaucher.org to learn more about how you can make a difference.

United Way and You

United Way is a non-profit organization that works to improve the lives of people in communities across the United States. They work to ensure that everyone has the opportunity to achieve their full potential, as measured by six key indicators of success: basic needs, education, health, financial stability, employment, and community engagement.

If you are interested in supporting United Way and making a difference in your community, please visit www.unitedway.org to find out how you can get involved today.

100% To Research

In 2004, United Way of America, in partnership with the National Conference of Christians & Jews, launched a major national campaign called the "United Way United \(100\%\) To Research" campaign. The campaign was designed to raise awareness and funds for research into diseases that affect the brain, including Alzheimer’s disease, Parkinson’s disease, and Lou Gehrig’s disease.

The campaign was a tremendous success, raising more than $50 million in donations from individuals, businesses, and organizations across the United States. The funds raised were used to support research into these diseases, helping to accelerate the development of new treatments and potential cures.

Thank you to all of those who supported the "United Way United \(100\%\) To Research" campaign and helped make it a success. Your support is making a difference in the lives of those affected by these diseases.

Summer 2004

The only thing incurable is our passion.

It is important to support the work of organizations that are committed to improving the lives of others. United Way is one such organization. By supporting United Way, you can help make a difference in your community and support the health and well-being of those in need.

Thank you for your support.

Mickey Timmer - Our Little Prince - Page 4

“Many times a day I realize how much my 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

Charity Golf Tournament

Working Until Midnight

Carol Astrue

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

With a machine as size and an engine as powerful as the one in the car, we were able to drive through the night. Our little prince was in the hospital, fighting for his life. We were determined to do everything we could to save him.

Carol Astrue

The winner of the 50/50 Cash Raffle was Deborah Macres R.N., a nurse at the Children’s Hospital. The hospital provided all the medical care that Mikkey needed, and they were always there for us.

The Gaucher Society of Canada

Mucolipidosis – etc.) Individually, lysosomal storage diseases affect 1 in 7000 births. Our challenge is to find a cure for these diseases, which are so rare that they often go unrecognized.

The Gaucher Society of Canada is dedicated to finding a cure for Gaucher disease. They are working tirelessly to raise awareness, provide support, and fund research into Gaucher disease and related diseases.

Thank you to all who have supported the Gaucher Society of Canada and the fight for a cure. Your support is making a difference in the lives of those affected by Gaucher disease.

Gaucher disease is the most common lysosomal storage disease, affecting about 1 in 50,000 people worldwide. The disease is caused by a deficiency in an enzyme called acid ceramidase, which causes the buildup of a compound called glucosylceramide in the body. This buildup of glucosylceramide can lead to a variety of symptoms, including organ enlargement, bone pain, and liver and spleen enlargement.

The Gaucher Society of Canada is working to find a cure for Gaucher disease, and they are making progress. They are also working to raise awareness and provide support for those affected by Gaucher disease.

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Gaucher disease is the most common lysosomal storage disease, affecting about 1 in 50,000 people worldwide. The disease is caused by a deficiency in an enzyme called acid ceramidase, which causes the buildup of a compound called glucosylceramide in the body. This buildup of glucosylceramide can lead to a variety of symptoms, including organ enlargement, bone pain, and liver and spleen enlargement.

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