



The Addi and Cassi Fund Presents:
Moonlight Garden Gala
A benefit for Childhood Alzheimer's (NP-C)

Sponsorship Package

www.AddiandCassi.com

Moonlight Garden Gala Event



The Addi and Cassi Fund Presents: **Moonlight Garden Gala** A benefit for Childhood Alzheimer's (NP-C)

Please join us for a star-filled night to help find a cure to “Childhood Alzheimer’s” (Niemann-Pick Type C), a rare, progressive and fatal neurological disease that is robbing children of all ages around the world of their ability to walk, talk, or even remember the name of their favorite stuffed animal.

The Moonlight Garden Gala at the new Downtown Reno Ballroom on Saturday, May 10, 2008 will be a mystical evening of hope, wonder and childhood dreams as we honor four-year-olds Addi and Cassi Hempel and children all over the world who suffer from “Childhood Alzheimer’s” (NP-C). Our guests will be treated to an elegant evening with a celebrity performance, silent and live auctions, uplifting music and an enchanting atmosphere as we transform the ballroom into a beautiful moonlit garden, designed in the spirit of a child’s imagination, with tree-lined paths, twinkle lights, fireflies and a fountain of wishes. This will be a very special evening where friends, family, honored guests and local dignitaries will have an opportunity to mingle, share ideas and help save children’s lives.

A Letter from Hugh and Chris



Dear Friends,

In October 2007 we received some devastating news. We learned that our lovely 4-year-old identical twin daughters – Addison and Cassidy – are afflicted with a rare and fatal childhood disease called Niemann-Pick Type C (NP-C). Frequently referred to as “Childhood Alzheimer’s”, NP-C causes progressive loss of brain function. There are virtually no treatments available for children with this disorder today.

From the moment we learned of the diagnosis, we decided to commit ourselves to finding near term drug therapies to treat NP-C and ultimately to find a cure for this devastating illness. Over the past few months, we have been working closely with doctors and scientists around the world. Collectively, we are making significant progress towards designing new therapies for our girls and all the kids afflicted with NP-C.

NP-C is a disease that crosses all ethnic boundaries. We have spoken with families all over the world who are fighting NP-C – from Australia to Japan to Pakistan. Most families have no access to medications and hopelessly watch their children lose their ability to walk, talk and eat. The only experimental drug available for NP-C children costs \$80,000 per year, per child. We want to change this situation.

Today, we are working in conjunction with the Mayo Clinic, the National Chemical Genomics Center (NCGC), the National Institutes of Health (NIH) and a variety of other organizations and research institutions to accelerate development of treatments for NP-C.

In order to reach our aggressive goals for NP-C kids, we have established The Addi & Cassi Fund within an existing non-profit organization called The Ara Parseghian Medical Research Foundation (APMRF). APMRF has been funding NP-C research for over 13 years and has made remarkable progress towards understanding the underlying mechanisms that cause NP-C. The focus of the Addi & Cassi Fund is to accelerate testing of therapies already identified in laboratories as potentially promising. In four short months, we are already gearing up for an unprecedented clinical study at the Mayo Clinic.

Please join us as a sponsor on Saturday, May 10th, 2008, at the new Downtown Reno Ballroom for a gala fundraiser that will include incredible entertainment, one of a kind auction items, and a who’s who of celebrities and top NP-C researchers.

With your help, we can find treatments quickly and ultimately a cure for NP-C children.

Thank you in advance for your support,

Handwritten signatures of Chris and Hugh Hempel. The signature on the left is in black ink and the one on the right is in green ink.

Chris and Hugh Hempel

■ SOUTH SUBURBAN



Addi and Cassi Hempel are shown as babies. Both have Niemann Pick Type C disease.

Searching for a cure



PHOTOS SUBMITTED TO THE RENO GAZETTE-JOURNAL

Chris and Hugh Hempel sit with their twin daughters, Addi and Cassi, who suffer from a rare childhood disease.

Twin girls living with a rare and often deadly disease are part of a study that could help many disorders

BY CARLA ROCCAPPIORE
croccaprio@rgj.com

A set of twin girls from south suburban Reno who are living with a rare disease are among those in a nationwide group study that could solve links to heart disease, stroke and other related conditions.

Addi and Cassi Hempel, both 3, were diagnosed with Niemann Pick Type C disease in October, their mother Chris Hempel said. There is no known cure.

NP-C, also referred to as "childhood Alzheimer's," causes cholesterol that the body naturally makes to build up and get trapped inside the cells, which eventually slows down cells and leads to cell death. Debilitating neurological and physical problems follow, such as not being able to walk, talk and eat.

"Right now, they're happy and healthy, but they have a time bomb clicking inside of them," Hempel said.

Addi and Cassi, who turn 4 next month, are taking part in a National Institutes of Health study and are on an experimental drug that is being covered by insurance, Hempel said.

The girls had mononucleosis and enlarged spleens two years ago. The mono was treated, but their spleens remained enlarged. Testing revealed Hempel and

"They have a time bomb clicking inside of them."

CHRIS HEMPEL ■ Her daughters have NP-C

her husband, Hugh, had family histories of heart disease and high cholesterol, and had the hereditary gene that causes NP-C.

Cholesterol is well understood in blood but not at the cellular level.

"The blood they take from them looks normal and doesn't appear to have anything wrong with it," Hempel said. "They took skin biopsies and molecular analyses of DNA."

Hempel and other members of the community are working with the Ara Parseghian Medical Research Foundation in Arizona to organize a Reno fundraiser for NP-C research.

Parseghian, 84, played for the Cleveland Browns in the late 1940s and went on to become a college football coach and sports commentator. He started the foundation in 1994 when three of his grandchildren were diagnosed with the disease. They since have died.

Hempel knows it's hard for people

HOW TO HELP

CURE CAPS PROJECT: Handmade knitted and crocheted hats made by volunteers for children and adults are being sought for those who make donations to NP-C research. The caps will be available online. Items can be sent to the Hempel family at 14125 Saddlebow Drive in Reno.

FUNDRAISER: A fundraiser for NP-C research is being planned for May at Silver Legacy Resort Casino, 407 N. Virginia St. Sponsors are being sought, along with items for a silent auction. Those interested in helping are asked to e-mail mariamuzee@charter.net or chris@hempelfamily.com

FINANCIAL CONTRIBUTION: Donate through the Ara Parseghian Medical Research Foundation at 520-577-5106 and specify the "Addi and Cassi Fund" or by mail to the Addi and Cassi Fund, care of Parseghian Medical Research Foundation, 3530 E. Campo Abierle, Suite 105, Tucson, AZ 85718. Contributions are tax deductible.

to understand why they should donate money to research a rare disease, but the implications are broad because finding a cure could also mean developments in the fight against more prevalent illnesses such as heart disease.

Reno doctor Susan Sorensen is treating the Hempel girls.

A Message from Addi and Cassi



Childhood Alzheimer's – Our Quest for a Cure! Help us fight a lethal cellular disease!

Cholesterol Disease Called NP-C

Who would ever think that a cholesterol disorder would cause a Childhood Alzheimer's syndrome that kills children? Well, that is exactly what is happening to us and other kids –right now, every moment of every day. Cholesterol is quickly building up inside each and every cell of our bodies. It is hurting our bodies including our brains, livers and spleens.

Our names are Addison and Cassidy Hempel. We're 4-year-old identical twins who were diagnosed on October 17, 2007, as having an uncommon and lethal genetic disease called Niemann-Pick Type C (NP-C). While curing this disease helps us, we also believe we might hold the keys to understanding cholesterol metabolism at the genome level. This ultimately could help you and your family.

Determined to Find a Cure

We don't yet understand why God chose for us to be born with NP-C disease but we are determined to find a cure that we hope will lead to medical breakthroughs in a number of areas. When researchers and scientists discover why this nasty cholesterol is building up inside our cells and destroying them, they may be able to make major breakthroughs for millions of people who suffer from Alzheimer's, heart attacks and strokes. We need help from people around the world to get the word out about Niemann-Pick Type C and to help us and other kids beat this devastating childhood illness.

Cholesterol Metabolism Failure Linked to Major Diseases

Today, we are vibrant young twins who love to sing and play. Tomorrow, we are faced with losing critical functions including the ability to walk, talk and eat. Many physicians refer to Niemann-Pick Type C as the "Childhood Alzheimer's" because both Alzheimer's and NP-C are progressive neurological diseases with similar effects on the brain. Some studies comparing the two diseases discovered that Alzheimer's could be tied to a failure in cholesterol metabolism – the very process that is a key component in NP-C. We all know that cholesterol issues are the main cause of heart disease around the world.

Our parents and friends are on a quest to find therapies and treatments in the near term and are working towards a progressive new treatment strategy for us. With everyone's help, we can conquer cholesterol and Childhood Alzheimer's together!

We Believe in Miracles!

With love,
Addi and Cassi



The Addi and Cassi Fund

Supporting Research Into Discovering Innovative Treatment
And Therapies For **ALL** Children Afflicted With NP-C

Where Does My Money Go?

The Addi and Cassi Fund, named in honor four year old identical twins Addi and Cassi Hempel, is building one of the first “*virtual pharmaceutical*” models in the United States and is focused on creating a drug therapy pipeline for Niemann-Pick Type C (NP-C)/Childhood Alzheimer’s afflicted children around the world. Every dollar you donate to The Addi and Cassi Fund goes directly to research projects that are rapidly accelerating finding innovative therapies and ultimately a cure for NP-C.

Of 7,000+ diseases that affect humankind, treatments for only 200 of these diseases are being actively pursued by pharmaceutical and biotechnology companies. With the cost of bringing a new drug to market now exceeding \$1 billion and taking up to 15 years to test and develop, global pharmaceutical companies are focused on return on investment. Meanwhile, millions of people suffering from all types of diseases will never see new drugs reach them or their loved ones in their lifetime. The “*virtual pharmaceutical*” model and highly personalized healthcare program being built by The Addi and Cassi Fund will become the model for the future and will directly help hundreds of children with no access to healthcare services or medicine.

Current Lifesaving Projects

America’s Robotic Heroes – The National Chemical Genomics Center Project

The Addi and Cassi Fund is working in conjunction with our nation’s National Chemical Genomics Center (NCGC) and leading doctors, scientists and research institutions around the world on an unprecedented project to tests thousands of available drugs and compounds that could be repurposed and used to treat NP-C children. Tests that would take an entire lifetime to conduct by hand can now be completed in a matter of days by robots. Our goal is to complete this project in 2008 and discover a known drug that can be administered to children immediately or find focused leads that with further research can turn into treatments.

Miracle Spice – The Mayo Clinic Project

Many researchers believe that neurological diseases ranging from Alzheimer’s to NP-C to Parkinson’s involve brain inflammation. An Indian spice used in curry dishes called Tumeric contains a compound known as Curcumin that is a natural anti-inflammatory agent. Researchers are in early pilot studies using Curcumin to treat disease. Through the support of Mayo Clinic’s leading pediatric genetic neurologist, Dr. Marc Patterson, a group of NP-C children are being studied on the Curcumin compound. The goal of this program is to get a inexpensive and free of secondary effects treatment into NP-C children around the world. When you consider it costs one family with two NP-C afflicted children \$225,000 per year for treatment, the potential for an essentially free and natural treatment with Curcumin is staggering.



The Brain Map Project - Children's Hospital Michigan

Dr. Harry Chugani, Chief of Pediatric Neurology at Children's Hospital of Michigan is the leading pediatric neurologist in the world conducting Positron Emission Tomography (PET) scans on children. Using a nuclear medicine imaging technique which produces a three-dimensional map of the brain, Dr. Chugani conducted first ever PET scans on Addi and Cassi and discovered unique results – a glucose metabolism problem in the frontal lobe which is common in adult dementia as well as inflammation in the parietal lobe and right caudate, an area often impacted in Parkinson's disease. **The Addi and Cassi Fund** is currently sponsoring a group of NP-C afflicted children to be part of the groundbreaking scientific imaging study but more funding is needed. Each glucose PET scans costs \$5,000 and is not covered by insurance and does not include travel to Detroit, Michigan, or hotel or rental car expenses. In addition, the **The Addi and Cassi Fund** will be working to fund the scans of NP-C children across disease states in the hopes that findings could lead to breakthroughs in Alzheimer's, Parkinson's and other neurological conditions.

Let's SOAR: Collaboration = Therapies = Cures!

The SOAR project (Support of Accelerated Research) is a unique research initiative where research scientists and clinicians carry out research together, *collaboratively*, with their focus squarely on the prize – finding therapies for NP-C now! Dr. Steven Walkley, a leading neuroscientist at Albert Einstein College of Medicine, and Dr. Daniel Ory, a professor and cholesterol and cell biology expert at Washington University in St. Louis, are leading the SOAR effort on translational research – studies that bridge the gap between the myriad of discoveries in cell biology and genetics in the laboratory with the need in medicine to find ways to intervene in the disease process and *treat* patients. Access to investigational drugs and disseminating information about investigational drugs is nearly non-existent in the medical field. For example, central data repositories even for common conditions do not exist and the organization of research is piecemeal and rarely directed in a collaborative manner among top researchers toward solutions. Cross fertilization among disciplines is not encouraged so that the wealth of information between disease states is not exploited. The SOAR project will serve as a model for collaboration for scientists everywhere.

The Stem Cell Neuron Project – University of California, San Diego

Dr. Larry Goldstein, a national leader in stem cell research and policy and director of the stem cell program at the University of California, San Diego is working on an unprecedented project to build Niemann-Pick Type C neurons. Dr. Goldstein's research is focused on understanding the molecular mechanisms of movement inside brain cells and how failures in the movement systems may lead to neurodegenerative diseases. His laboratory has discovered important links between transport processes and diseases such as Alzheimer's and Huntington's diseases. He is now working to understand NP-C neurons in an effort to create breakthroughs not only for NP-C but millions of Alzheimer's patients.

The AIDS and NP-C Project – Cholesterol is the Culprit

Dr. James Hildreth is the Director of the Meharry Center for AIDS Health Disparities Research. At the heart of Dr. Hildreth's studies is the hypothesis that cholesterol, and the proteins that produce cholesterol and control it in cells are critical for many viruses. The list of viruses for which cholesterol played some role in their replication in the human body is long. Given NP-C's essential role in cholesterol functions in cells, Dr. Hildreth has a deep interest in the disease. His studies have the potential to shed light on both HIV/AIDS and the biology of Niemann-Pick Type C. Dr. Hildreth believes that a new AIDS drug, and possibly a drug useful for NP-C patients may come out of his research work. He is currently seeking \$1 million over the next 3-5 years from the NIH and other sources.

The Addi and Cassi Fund exists within the framework of the Ara Parseghian Medical Research Foundation (APMRF). The APMRF is a 501(c)(3) non-profit organization named in honor of Ara Parseghian, the much beloved and well-known Notre Dame football coach, who had three grandchildren pass away from NP-C. APMRF has raised over 30 million dollars for support into NP-C research.



Research Advancements

Virtual Pharmaceuticals Small Teams Conducting Industrial Scale Science

The Idea Behind The Virtual Pharmaceutical Model

Using cutting edge technology and industrial engineering principles, “Virtual Pharmaceuticals (VPs)” reduce the time, cost and risk of bringing new drug therapies to patients with neglected and rare diseases. VPs work directly with academic researchers, since commercial development is not economically viable for pharmaceutical companies. With the cost, scale, and complexity of drug development beyond the reach of most academic labs, the “VP” model, new companies like Silicon Valley’s CollabRX, looks to ease this situation.

CollabRX provide research teams with management services and the IT infrastructure needed to function as an effective virtual company. CollabRX’s Virtual Pharmaceutical openly shares its knowledge and resources, then coordinates their search for targets and leads. By using a shared ecosystem of outsourced services, their “VP” model makes it cost-effective for small groups of academic researchers to conduct industrial scale science. Because VPs can be set up quickly and inexpensively, they can be funded by “patient capital” supplied by investors with a specific interest in a disease: foundations, groups of like-minded patients, or even individuals. Another benefit to VPs is the ability to instantly restructure resources and projects as needed for optimal results.

Corporate Sponsorship Levels



The Addi and Cassi Fund Presents: Moonlight Garden Gala

Saturday, May 10, 2008 at the new Downtown Reno Ballroom

Pre-Event Golf Tournament

Friday, May 9, 2008 at Montrêux Golf & Country Club

To Benefit Childhood Alzheimer's (NP-C) through the Addi and Cassi Fund
(Part of the Ara Parseghian Medical Research Foundation)

TITLE SPONSOR

- Premier seating at two tables of eight (16 seats)
- Company logo & name prominently displayed on stage and given prominence in our event video & multimedia production
- Charter promo airtime with prominent logo and voice acknowledgement
- Full page ad in event program in location of your choice
- Four tickets to VIP *Meet and Greet* Party
- Eligibility for four to Friday afternoon private, all-inclusive golf tournament, evening awards dinner and entertainment
- Advertising on the golf course first hole during tournament
- Web site homepage "thank you" at AddiandCassi.com
- Company logo and/or name featured on our formal invitation

PLATINUM SPONSOR **\$16,000**

- Premier seating at one table for eight
- Company logo & name featured in full page ad in event program; also displayed in our event video & multimedia production
- Charter promo airtime with prominent logo
- Two tickets to VIP *Meet and Greet* Party
- Eligibility for two to Friday afternoon private, all-inclusive golf tournament, evening awards dinner and entertainment
- Advertising on the golf course during tournament
- Web site homepage "thank you" at AddiandCassi.com
- Company logo and/or name featured on our formal invitation

DIAMOND SPONSOR **\$12,000**

- Reserved seating at one table for eight
- Company logo & name featured in half-page ad in event program; also displayed in our event video & multimedia production
- Charter promo airtime with prominent logo
- Two tickets to VIP *Meet and Greet* Party
- Eligibility for one to Friday afternoon private, all-inclusive golf tournament, evening awards dinner and entertainment
- Advertising on the golf course during tournament
- Web site homepage "thank you" at AddiandCassi.com
- Company logo and/or name featured on our formal invitation



Corporate Sponsorship Levels

GOLD SPONSOR \$8,000

- Reserved seating at one table for eight
- Company name featured in half-page ad in event program; also displayed in our event video & multimedia production
- Two tickets to VIP *Meet and Greet* Party
- Eligibility for one to Friday afternoon private, all-inclusive golf tournament, evening awards dinner and entertainment
- Web site homepage “thank you” at AddiandCassi.com
- Company logo and/or name featured on our formal invitation

SILVER SPONSOR \$6,000

- Reserved seating at one table for eight
- Company name featured in half-page ad in event program; also displayed in our event multimedia production
- Two tickets to VIP *Meet and Greet* Party
- Eligibility for one to Friday afternoon private, all-inclusive golf tournament, evening awards dinner and entertainment
- Web site homepage “thank you” at AddiandCassi.com

RUBY SPONSOR \$4,000

- Reserved seating at one table for eight
- Company name featured in quarter-page ad in event program; also displayed in our event multimedia production
- Eligibility for one to Friday afternoon private, all-inclusive golf tournament, evening awards dinner and entertainment
- Web site homepage “thank you” at AddiandCassi.com

EMERALD SPONSOR \$2,400

- Reserved seating at one table for eight
- Company name featured in event program; also displayed in our event multimedia production
- Web site homepage “thank you” at AddiandCassi.com

SAPPHIRE SPONSOR \$1,400

- Reserved seating at one table for eight
- Company name featured in event program
- Web site homepage “thank you” at AddiandCassi.com

Sponsorship/Donation Form



The Addi and Cassi Fund Presents: **Moonlight Garden Gala** A benefit for Childhood Alzheimer's (NP-C)

Niemann-Pick Type C is a fatal disease often referred to as "Childhood Alzheimer's". NP-C is caused by the uncontrolled buildup of cholesterol in the cells of the body and it robs children of the ability to walk, talk or even remember the name of their favorite stuffed animal. Please visit Addi and Cassi's site at: www.AddiandCassi.com

Fundraising Event: The New Downtown Reno Ballroom, May 10, 2008

Name _____ Date _____

Business Name _____

Address _____

City _____ State _____ Zip Code _____

Phone _____

Donation Item _____

Program Description _____

Value of Donation _____

Sponsorship Level _____

The family and volunteers for the Addi and Cassi Fund sincerely appreciate your generous donation in helping find a cure for NP-C.

Please make checks payable to "APMRF –The Addi and Cassi Fund"
Non-profit 501(c)(3) tax classification, Tax ID# 86-0775966

[800] 517-2542 • info@addiandcassi.com
14125 Saddlebow Drive • Reno, NV 89511

