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SPRING 2008

A GOAL FOR LIFE

For Friends and Supporters of the Ara Parseghian Medical Research Foundation



Jessica Leoni Kevin Eadie Ty Quandt Andrew & Dana Marella Joshua Jacoby Bojarsky Adam Recke Addi & Cassi Hempel Emily Sanda Casey Kahl Kayla & Peyton Hadley

A Legacy of Hope

Dear Friends,

Hope springs eternal, and the seasonal promise of new life is especially poignant for children and families impacted by Niemann-Pick Type C.

Looking back, we find it hard to believe that it has been 14 years since our children were diagnosed with NP-C; while sometimes it seems like a lifetime, often it feels like only yesterday.



Amy Grant, Cindy Parseghian, Vince Gill, Michael & Ana Parseghian

And though Michael, Christa and Marcia are no longer with us, we can still hear their wonderful laughter, see their sparkling eyes and feel their little arms hugging us. While we miss them unbearably, they inspired a legacy of hope.

Hope lies at the heart of the support from people around the world who have reached out to touch our lives, from elementary school students who

have donated pennies and high school students who have staged fundraising walks to Notre Dame alumni clubs that have organized golf tournaments and benefits. Sports legends and celebrities have championed our cause.

At the upcoming "One More Victory, Ara!" Golf Tournament and Gala, country music legend Vince Gill will once again perform. He and his wife, Amy Grant, have embraced the families and children battling NP-C with their ongoing support of our annual fundraiser in Tucson.

Hope is alive through your unflagging support and unprecedented generosity which in turn has enabled us to fund cutting edge research in 23 labs around the world—research that may have implications not only for those with NP-C, but for those with Alzheimer's and other cholesterol metabolism disorders. Your generosity will allow us to continue to support grants and endow research for these devastating diseases.

To all of you, we salute you. You have not only built the APMRF alongside us; you have built a legacy of hope for families of children with NP-C and other genetic neurodegenerative diseases—a testament to the strength and resilience of the human spirit and to the miracles that can be accomplished when people come together with a goal for life.

Sincerely, Cindy and Mike

Zinburger Opening Benefits APMRF



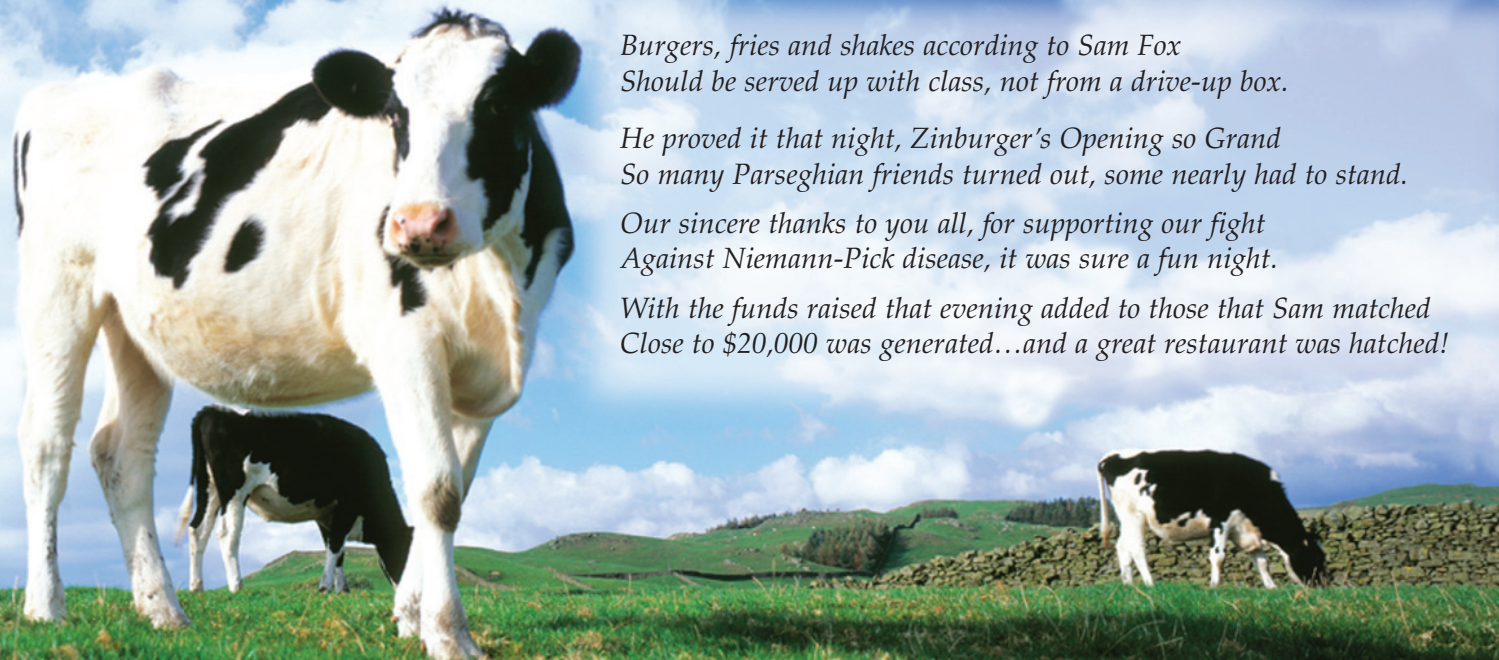
Zinburger, Fox Restaurant Concept's newest concept, opened in Tucson in December 2007 with the evening benefiting the Parseghian Foundation. Thank you to Sam Fox and to all who attended this festive event.

*Burgers, fries and shakes according to Sam Fox
Should be served up with class, not from a drive-up box.*

*He proved it that night, Zinburger's Opening so Grand
So many Parseghian friends turned out, some nearly had to stand.*

*Our sincere thanks to you all, for supporting our fight
Against Niemann-Pick disease, it was sure a fun night.*

*With the funds raised that evening added to those that Sam matched
Close to \$20,000 was generated...and a great restaurant was hatched!*



Nobel Prize Winners to Speak

The Parseghian Foundation is honored that Drs. Michael Brown and Joseph Goldstein will deliver Plenary Lectures at the 2008 Scientific Conference on Niemann-Pick Type C Disease on June 5-7, 2008. This important NP-C Conference takes place in Tucson each year hosted and sponsored by the APMRF.

As colleagues, Drs. Brown and Goldstein discovered the low density lipoprotein (LDL) receptor and worked out how these receptors control cholesterol. This groundwork led to the development of drugs called statins that lower blood cholesterol and prevent heart attacks.

Drs. Brown and Goldstein shared many awards for this work, including the Nobel Prize in Physiology or Medicine in 1985 as well as the National



Drs. Michael Brown and Joseph Goldstein

Addi and Cassi Hempel



Chris and Hugh Hempel loving on their identical twin daughters, Addi and Cassi.

Six months ago, Chris and Hugh Hempel were flung head-first into the role of activists when their four-year-old twin daughters, Addison and Cassidy, were diagnosed with NP-C.

“Our entire world came crashing down on October 17, 2007,” says Chris, of what is believed to be first-ever NP-C diagnosis of identical twins in the US.

The dynamic couple, who met at Netscape in 1996 and moved to Reno, Nevada, in 2002, set aside their heartbreak and immediately took action against the disease that is often referred to as “childhood Alzheimer’s.”

With Addi and Cassi’s lives at stake, the Hempels are on a mission to help accelerate drug development and find new therapies for victims of all diseases—and to make cost-prohibitive drugs accessible to people around the globe who need them.

“Our story is not just a story about two twins dying from a rare disease. We want people to know this same situation might happen to them or someone that they love in the future. You don’t need to have a rare disease to end up in this situation with no drug options.”

The Hempels are teaming with experts at the National Institutes of Health, Mayo Clinic and other medical institutions and have pooled resources with the APMRF to expedite pharmaceutical clinical trials and research. They have established a special fund at the Parseghian Foundation called “The Addi & Cassi Fund”.

Along with many volunteers and friends, they are hosting their first annual fundraising event in Reno on May 10 titled “Moonlight Garden Gala – A Night for Hope and Miracles.” Featured entertainment will include American Idol finalist Melinda Doolittle and America’s Got Talent winner Terry Fator.

The Hempels have joined with the Parseghians and many other families in the passionate battle against Niemann-Pick Type C disease. Our thanks to Hugh and Chris for the amazing energy and time they have dedicated to the fight on behalf of precious little Addi and Cassi...and all children living with NP-C.



Dad shows Addi and Cassi the bunny.

Nobel Prize Winners

(cont'd. from page 1)

Medal of Science in 1988. Both are professors and departmental leaders at the University of Texas Southwestern Medical Center at Dallas.

It is very exciting for the Niemann-Pick community that Drs. Brown and Goldstein as well as those in their extensive lab have become involved with NP-C research and how it may relate to cholesterol. The APMRF is currently funding Dr. Guosheng Liang, a member of the Brown and Goldstein Laboratory.

They recently published a paper in *The Journal of Biological Chemistry* titled “Purified NPC1 Protein: I. Binding of Cholesterol and Oxysterols to a 1278-Amino Acid Membrane Protein.”

We welcome Drs. Brown and Goldstein and their lab associates and thank them for the stature, interest and knowledge their involvement brings to the NP-C field in our quest to find a treatment for this disease.

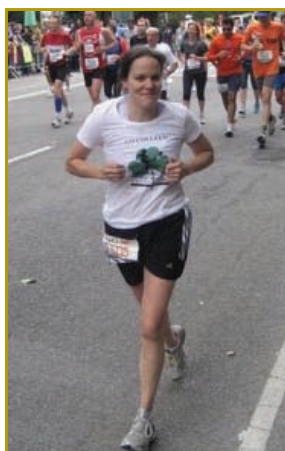
Heartfelt Thanks...

Our sincere thanks to the many volunteers around the country who help raise funds and awareness for NP-C research. Here are a few we'd like to acknowledge:



Notre Dame Glee Club members sing out.

“Sounds of Hope” was a befitting title for a special combined performance of the University of Notre Dame Glee Club and the Sound of the Rockies held in Denver, CO. The first-time event was the brainchild of Marcia Mueller, sister to Cindy Parseghian, and Notre Dame alumni Bob Kelley...both avid supporters of the APMRF. It was truly a night to remember.



Colleen Weigle runs for the APMRF.

Another Notre Dame alumni, Colleen Weigle, not only has a strong heart from being a marathon runner...she has a kind heart as well. While an undergrad at Notre Dame, Colleen organized a 5K Run/Walk to benefit the APMRF. Last fall she carried on this tradition of caring by running in the NYC Marathon with her sponsorships benefitting the APMRF. Our thanks to Colleen for continuing the fight against NP-C disease.

It says a lot when boosters from a high school take part of the funds they have raised for their school’s sports program and give them to fund NP-C research. The Sycamore HS Athletic Boosters in Cincinnati, OH did just that. They invited Coach Parseghian to attend their annual dinner where he was the featured speaker. In return, they showed their appreciation and support by donating \$7,500 to the APMRF.

Five states west of Ohio in the little community of Monte Vista, Colorado another civic group showed their support for the fight against NP-C. The Magnolia Society, a women’s group based in Monte Vista, presented a check for the APMRF to Fran Herrera, grandmother of sweet little Mario Najera, who is afflicted with NP-C.

Mary Wright, Valarie Barilleaux, Rani Bush and Elona Lathrop know the meaning of lasting friendship. When these four friends were informed their friend’s son, Ty Quandt, was afflicted with NPC disease, they started the Niemann-Pick Benefit Concert and Silent Auction now in its 3rd year. They have organized and promoted the event enlisting the support of the Las Vegas and St George, Utah communities, raising more than \$30,000 for research.



APMRF Admin. Asst. Susan McDonald, Jim Click and Karen Sarikas, APMRF Volunteer Accountant, stand by the Mustang “Bullitt”.

In his continuing support of the Tucson community, local car dealer Jim Click donated a 2008 Ford Mustang “Bullitt” in hopes that \$1 million dollars could be raised by Tucson charities through the sale of raffle tickets. Each charity kept the proceeds from their sales. Thanks to the generosity of Jim Click and our many friends, the APMRF was the top seller for this and the previous two raffles raising more than \$125,000 in total.



Chance Ward and Charles Allen

Michael Parseghian loved karate.

When Mike and Cindy Parseghian attended the 25th Anniversary Extravaganza for the Ultima Martial Arts Center in Tucson, AZ on January 19, it brought back special memories of the hundreds of visits they made to the studio with their children. Owner and instructor Charles Allen was a hero to the Parseghian children. He and current manager Chance Ward, equally dedicated to helping children, hosted a wonderful day of brick breaking, karate demonstrations, games and food booths...all benefiting the APMRF.

Stanford NP-C Researchers

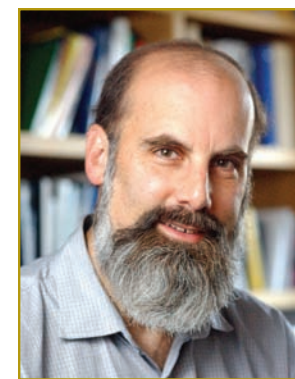
“The APMRF is very special and unusual because of the community of scientists they nurture and their approach of encouraging information and idea exchanges through annual meetings and other means. When scientists work together, the potential for discovery—and the pace—is greatly enhanced,” said Suzanne Pfeffer, Ph.D., a researcher at Stanford University who has been funded by the APMRF since 2002.



Dr. Suzanne Pfeffer

well as possibly victims of other neurodegenerative diseases and lysosomal storage disorders.

Pfeffer said she has been influenced and inspired by the work of Matthew Scott, Ph.D., another Stanford scientist who has been funded by the APMRF for the past decade. Dr. Scott also serves as a member of the APMRF’s Scientific Advisory Board.



Dr. Matthew Scott

Pfeffer’s lab has engineered specific portions of the NPC-1 protein and is working to provide a purified protein with which biologists can determine the protein’s three-dimensional structure; this in turn will provide invaluable information for optimizing future drug design and therapies for NP-C patients as well as possibly victims of other neurodegenerative diseases and lysosomal storage disorders.

Scott’s lab is investigating the functions of NP-C proteins in the vital Purkinje neurons of the cerebellum. Purkinje neurons gradually die when NP-C proteins are not working properly and little is understood about the role NPC proteins play in these neurons; however, their loss is critical since the cerebellum helps coordinate body movements and functions such as language.

Along with former associate Dr. Xun Huang, Scott’s lab constructed genetic models of NP-C disease in the classic Drosophila, a type of fruit fly.

“Humans and Drosophila had a common ancestor about half a billion years ago and it is a measure of how fundamental NPC proteins are to cell functions that in insects and mammals they still have similar functions: if NPC proteins are not working properly in either, the cells will accumulate sterols and neurons will be damaged. The hope for the fly model is that powerful genetics can be used to identify genes that interact with NPC proteins,” Scott said.

He believes the fast track toward a treatment for NP-C may require a two-pronged assault, an approach that the APMRF champions. “I think another worthwhile approach to find a treatment is to search for potential drugs the way drug companies do: by using huge collections of chemicals and testing them on NP-C mutant cells. Sometimes a chemical can be found that helps to repair cells, even without full understanding of NP-C protein functions.”

“Thus two parallel lines of work can go forward: screening for drugs while developing new measures of cell functions to do the screens, and exploring the molecular and cellular mechanisms of NP-C protein functions. No one can tell which approach will succeed first, and both are worthwhile,” Scott said.

Mark Your Calendar

April 19, 2008 – Catalina Foothills High School Student Council in Tucson will host their 4th Annual “One More Victory, Ara! 5K Walk/Fun Run” in memory of their friend and classmate, Marcia Parseghian. For information contact Alex Deo at CFHSwalk@mac.com.

April 25-26, 2008 – The 13th annual “One More Victory, Ara!” Celebrity Golf and Gala Weekend Presented by University Medical Center will be held at The Westin La Paloma Resort & Spa in Tucson, AZ. For information call the APMRF: 520-577-5106.

May 9, 2008 - Fiesta Fantastica at La Encantada in Tucson, AZ sponsored by Tucson Lifestyle Home & Garden and La Encantada, and presented by Chapman Automotive. A festive evening of delicious food, beverages and music to benefit the APMRF. To purchase tickets call: 520-299-3566.

May 10, 2008 – Moonlight Garden Gala at the Silver Legacy Ballroom in Reno, NV. A celebrity performance, auction and dinner to benefit the Addi and Cassi Hempel Fund at the APMRF. For information visit: www.AddiandCassi.com.

June 14, 2008 - Allentown, PA will be the site of the third annual “5K Run/Walk for a Cure” hosted by family and friends of Adam Recke, an eight-year-old boy with NP-C. Contact Matt Tobias: 610-390-5602.

July 21, 2008 – Notre Dame Club of Milwaukee’s Ara’s Outing 2008, Mequon Country Club in Mequon, Wisconsin. Join Notre Dame members and celebrities for golf, dinner and an auction. Contact Tom or Terry Mulcahy: 1-800-711-6132.

July 31, 2008 – Third annual “Notre Dame Coaches’ Kickoff for Charity,” at the Palmer House Hilton in Chicago, IL. To benefit the foundations of coaches Parseghian, Weis and Holtz. Contact the APMRF: (520) 577-5106.

August 4, 2008 – The second annual “Irish Legends” Golf Tournament will take place at the Lost Dunes Golf Club in Bridgman, MI to benefit the APMRF and The Holtz Charitable Foundation. For information on this fun golf outing, dinner and auction contact Angela Monger: (800) 628-9922 Ext. 503.