



ARA PARSEGHIAN
MEDICAL RESEARCH
FOUNDATION
 A GOAL FOR LIFE

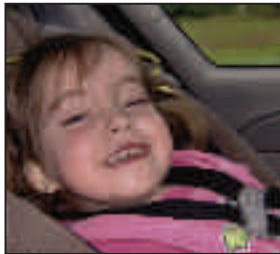
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A GOAL FOR LIFE

THE NEWSLETTER OF THE ARA PARSEGHIAN MEDICAL RESEARCH FOUNDATION

SEASONS GREETINGS...

To our many friends who are helping us
 bring hope to these and all NP-C children
 and families around the world.



Riley Corbitt, Woodville, AL



Addi & Cassi Hempel, Reno, NV



Ty Quandt, Edgewood, WA

Building Important Therapeutic Collaborations

In its commitment to finding a treatment and cure for NP-C, the APMRF is building partnerships and developing collaborations with implications for all genetic neurodegenerative diseases.

One such APMRF-funded collaboration project is the team comprised of Frederick Maxfield, Ph.D., Chairman of the Department of Biochemistry at Weill Medical College of Cornell University in New York, Paul Helquist, Ph.D. and Olaf Wiest, Ph.D., Professors in the Department of Chemistry at University of Notre Dame, and Steve Walkley, D.V.M., Ph.D., Professor of Neuroscience at the Albert Einstein College of Medicine.



Dr. Fred Maxfield

The APMRF began funding Maxfield, who has a longstanding research interest in cholesterol, in 2001 after he became aware that his work might be directly applicable to understanding NP-C.

Maxfield has discovered several different classes of compounds with promising effects on NP-C cells in culture, and is now pursuing further steps and testing the most promising compounds for toxicity in mice. He is also determining the cellular mechanisms by which several of these compounds work to

help prioritize which groups of compounds to pursue most vigorously.

A unique opportunity to take Maxfield's findings to the next level presented itself several years ago at an annual NPC Scientific Conference hosted by the APMRF, attended by Helquist and Wiest. The Notre Dame chemists proposed they form a collaboration to provide the medicinal chemistry to take Maxfield's compounds toward possible drug development.



Dr. Olaf Wiest

Helquist's chemistry expertise allows the team to create additional compounds related to the first "hits," and as the molecular targets of the compounds are identified, Wiest's proficiency in computer modeling illustrates the method in which chemicals bind to these targets.

This process leads to ideas for improved compounds that can be formulated in Helquist's laboratory, tested by Maxfield and eventually passed along for testing in NP-C mice with APMRF-funded researcher Steve Walkley of Albert Einstein College of Medicine.

(cont'd. on page 2)

WINTER 2007

HEARTFELT THANKS



"Irish Legends", a golf tournament honoring Ara Parseghian and Lou Holtz and benefiting the APMRF and the Lou Holtz Foundation, took place on August 6, 2007 in **Olympia Fields, IL**. Tournament Chairmen Skip Strzelecki and Jim Moriarity organized a fabulous event that brought together a great group raising significant dollars for great causes. The energy and enthusiasm of all involved made for a successful event that is being repeated in 2008. Many thanks to Skip and Jim for their ongoing support and effort.

Another great golf event took place in the **Chicago area**. **Vince and Josephine Tenuto** have hosted the "**Ara Parseghian Charity Golf Day**" for the past eight years. This year's tournament took place on August 17 at Gleneagles Country Club and was a success raising more funds than ever before.

Holly Bell, who gave dance lessons to Michael, Marcia and Christa Parseghian for many years, once again held her annual **International Food Fair and Open House** to benefit the APMRF on November 3 in Tucson...great job Holly and thanks so much for your continued love and support!



Shawn Parr gives Jessica Leoni a big hug.

The 9th annual "**Fight For Jessica**" event held on November 10 at the Manhattan Beach Marriott in **Southern California** was an evening of family, friends and hope. Anthony and Lisa Leoni and daughter Jessie brought together over 350 people who share their vision of "Dream it, Believe it, Live it....". The "**Jessie Girls**", a group of dance students and friends to Jessie, added their magical touch

(cont'd. on page 5)

Building Important Therapeutic Collaborations (cont'd. from page 1)

"So with the screening and follow-up cellular testing in my laboratory, the chemistry and computer modeling at Notre Dame and the animal testing at Albert Einstein, we now have the key parts of an interdisciplinary team for the early stages of drug discovery," Maxfield says.



Dr. Steve Walkley

While he is realistic about the fact that many promising therapies fail at some stage and that momentous diligence, effort and patience are needed to test compounds in animal models and possibly patients, Maxfield is optimistic about the potential new classes of molecules that may lead to new therapies.

He is also excited about his role within the team of scientists working thoughtfully toward optimizing treatment for NP-C and possibly other cholesterol-related diseases.

"Until the past few years my laboratory research was entirely focused on basic science. I had hoped that others would take our discoveries in fundamental science and use these to develop therapies. It has become increasingly clear that basic scientists need to think about ways to translate their discoveries into medicines themselves. It is very exciting to think about being involved in the early stages of developing new treatments for NP-C," Maxfield says.

You've Carried Us... The Team Carried

Dear Friends,

As we sat there at Notre Dame Stadium with our Parseghian relatives and hundreds of Ara's friends and former players when the sculpture of Ara was unveiled, we were touched by the symbolism between the sculpture and our journey over the past thirteen years.

When Grandpa Ara was first approached about a sculpture being created to honor his era at Notre Dame, he told them no. Ara did not want a single statue of himself representing his eleven years as head coach of the Fighting Irish. To him it was a combination of a lot of people, teamwork, coordination, and the sacrifices that made it happen. Thus the team sculpture was created.

Like Ara, when someone comments on our strength to have made it through the death of three children or about the success of the Foundation, we are quick to say that it was only possible due to the incredible support we've been given.

As depicted by the statue, Ara's players carried him off the field following Notre Dame's famous victory over Texas in the 1971 Cotton Bowl. You have carried us on your shoulders with your love, prayers and generosity.

Your support gave us the strength to go on...and continues to give us the passion to conquer NP-C disease so other families do not experience what we have. Thank you so very much.

We wish you a Joyous Holiday, and a Healthy and Happy New Year.

Cindy and Mike Parseghian



Michael, Cindy, Ara, Katie, Ara and Cicely Parseghian.



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FRIENDS RALLY FOR ADAM...

Adam Recke has touched the lives of many people in Western Pennsylvania. Many individuals and organizations have rallied around him in the fight against NP-C disease.

Several events have taken place in the past several months raising awareness and funds to speed research toward a treatment and cure.

More than \$10,000 was raised from the 2nd Annual "Golf for a Cure" sponsored by the Pennsylvania State Education Association, of which Adam's father is a member. Bob Creveling and Maureen Foster did a great job organizing and promoting the tournament.

Two other dedicated volunteers, Casey Stengel and Carol Laub, organized a Poker/Bike Ride and Family Picnic raising \$11,000 from their first event. Congratulations and thanks for hosting this unique event!

As noted in the photo, Sean Recke's fellow teachers at Salisbury Middle School in Allentown, PA decided to hold a Wolfman Contest to raise money for research. Each teacher who entered the contest had to stop shaving. The student and staff donated money to their favorite Wolfman with those collecting the least amount of money eliminated from the contest. Matt Tobias, who has been very involved in the Fight For Adam, was the winner.

Our sincere thanks to everyone who has shown their love and support to the Reckes and all families living with NP-C disease.



Gregg Laub, Matt Tobias, Sean Recke, Mike Posch, and Gary Schweyer.

with a beautiful and touching dance performance. Thanks to the master of ceremonies, Shawn Parr of KKGO Country in Los Angeles, who once again provided his time, talent and friendship. Thank you to all whose help provides the most treasured gift of hope. It gives all families living with NP-C the strength and courage to continue.

Tiffany & Co at La Encantada in Tucson, AZ was the enchanting location for a festive evening of tasting, toasting and shopping!



Friends of the Foundation enjoy a festive evening at Tiffany and Company.

This event, hosted by Tiffany & Co, provided guests with an opportunity to view the *Masters of Tiffany Design*. A portion of the evening's proceeds benefited the Foundation. Since their arrival in Tucson, Tiffany & Co has been a partner and valued friend in our quest to fight NP-C disease.

CALENDAR

OF UPCOMING EVENTS

1

January 26, 2008 - Verna Burrows, a grandmother of an NP-C child, and her friends in **Las Vegas** are hosting their 3rd annual **"Touchdown for Ty"**. This family-oriented variety program will feature musical and dance acts. A silent auction and reception will also be part of the festivities. Call Verna Burrows: (702) 363-5443.

2

April 19, 2008 - Catalina Foothills HS Student Council in **Tucson** will host their 4th Annual **"One More Victory, Ara! 5K Walk/Fun Run"** as well as a benefit concert that evening in memory of their friend and classmate, Marcia Parseghian. Call Alex Deo at 520-990-0226.

3

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**. Call the APMRF office: (520) 577-5106.

4

May 16, 2008 - Fiesta Fantastica Presented by Chapman Automotive at La Encantada in **Tucson** sponsored by **Tucson Lifestyle home & garden** and **La Encantada**. It's a festive evening of delicious food and beverages along with colorful pinatas and music to benefit the APMRF. To purchase tickets call: 520-577-5106.

5

May 18, 2008 - Allentown, PA will be the site of the 3rd annual **"5K Run/Walk for a Cure"** hosted by family and friends of Adam Recke who has NP-C. Contact Matt Tobias: 610-390-5602.

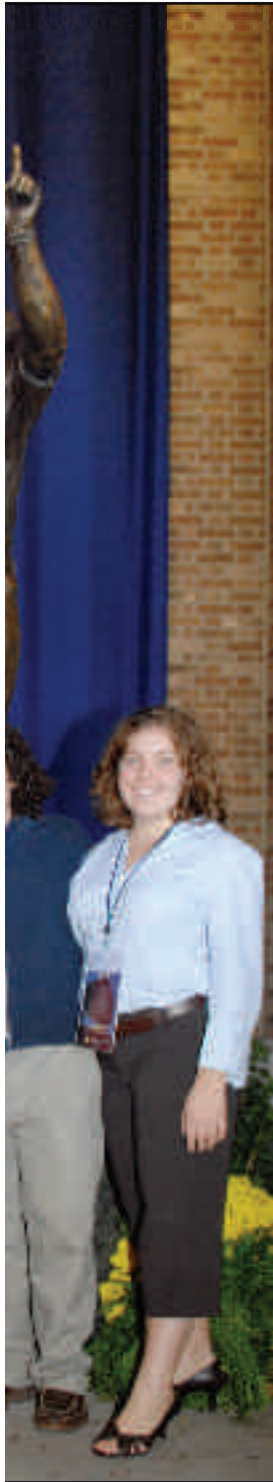
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August 1, 2008 - The third annual **Notre Dame Coaches' Kickoff for Charity** will take place at the Palmer House Hilton in **Chicago, IL** to benefit the foundations of coaches Parseghian, Weis and Holtz. Call 520-577-5106.

7

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

ed Ara



THE FINAL BATTLE

"Adversity elicits talent which under prosperous conditions would have remained dormant."

With every setback on the football field, and especially in day-to-day living, Ara Parseghian would remind himself of that one sentence.

He discovered resolve and untapped talent within himself, and others, after a 0-9 season at Northwestern in 1957. He did the same at Notre Dame, winning a national title 364 days after a 40-6 loss to Nebraska in the 1973 Sugar Bowl.

Yet football results pale in comparison to burying three children or, in his case, grandchildren.

In November 1994, two months after learning that three of their four children had a rare, fatal, genetic disease called Niemann-Pick Type C (NP-C), Cindy and Michael Parseghian, and a cadre of volunteers founded the Ara Parseghian Medical Research Foundation.

"I'm trying to slow down, frankly, because that kind of comes with being in your 85th year," Parseghian said. "But new drugs are coming into clinical trial, we've isolated the defective gene, we have a diagnostic test...that's a lot in the field of research for an orphan disease. We're proud of that.

"In terms of a football analogy, we've gone from our one-foot line to just past midfield, and we're nearing four-down territory."

Alas, the valiant effort wasn't enough to save Cindy and Michael's three youngest children. Michael, 9, lost his battle with NP-C in 1997. Christa, 10, passed away in 2001. Marcia, 16, died in 2005.

"We're all scarred from this experience," said the eldest Parseghian. "I would be driving in the car by myself and I would break down. Here are two wonderful parents that are raising their children in the proper American way, wonderful human beings – why would this happen to them, and why did the poor grandchildren have to go through it? That I can't understand and never will be able to."

But just because the Parseghians lost their personal battles doesn't mean the campaign is going to fold. To honor the legacy of Michael, Christa and Marcia, they remain committed to finding a cure to prevent future anguish for other families.

"There's no question being involved with competitive athletics has helped me with this," Parseghian said. "You get knocked down, you have to get up, particularly in football because the very nature of the game is physical, mental, strategic, emotional, all those things."

Although he is still the chairman of the foundation, Parseghian points to daughter-in-law Cindy as the mainstay of the behind-the-scenes efforts. Along with Dr. Michael Parseghian, who was a walk-on running back for his father's final squad at Notre Dame in 1974, they are committed to waging the good fight.

"Do I have faith we're going to find a solution? Yes. Did we get the silver bullet before our grandchildren were gone? No, but we're still hopeful of finding a cure so other parents and grandparents and children won't have to suffer under this agony of this doggone disease."

- by Lou Somogyi, Senior Editor
Blue & Gold Illustrated