FALL 2008

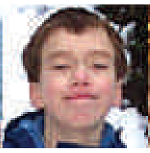
A GOAL FOR LIFE

For Friends and Supporters of the Ara Parseghian Medical Research Foundation

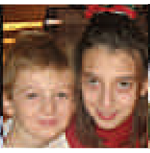
Ara Parseghian
Medical Research
Foundation
A GOAL FOR LIFE

Jessica Leoni

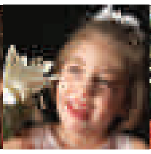
Kevin Eadie



Ty Quandt

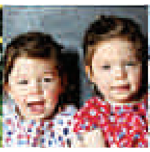


Andrew & Dana Marella



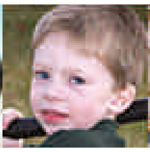
Ashton Friedl

Adam Recke

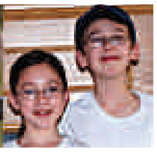


Addi & Cassi Hempel

Emily Sanda



Casey Kahl



Kayla & Peyton Hadley

Coach's Corner

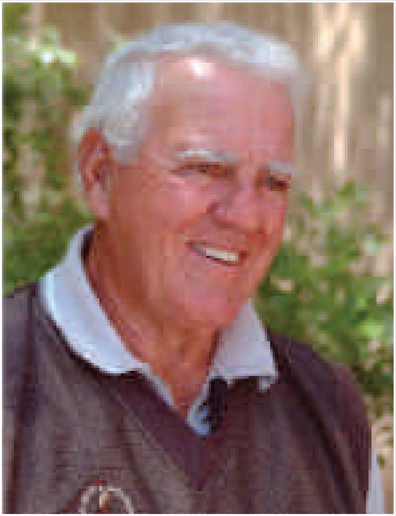
Dear Friends,

I am so very grateful for the continued generosity of so many wonderful people who have stepped forward to help us over these past fourteen years.

From Notre Dame alumni to civic organizations, and from school groups to the band Chicago… I can't begin to express how much this support has meant to our family and to all families afflicted with Niemann-Pick disease.

As well, many NP-C families and their friends have held fundraising events of all kinds around the country contributing hundreds of thousands of dollars to push the ball further down the field in hopes that a treatment will soon be found. This is our goal.

Although I continue to be involved in the work of the Foundation—I am pleased to say the leadership of the Foundation is in the capable hands of my daughter-in-law, Cindy, who has been the President of the Foundation since the start.



Ara Parseghian

We also have three others on our Foundation team, two of whom work part-time, as well as more than 80 dedicated volunteers in Tucson and around the country.

As a coach, you know the importance of each player on the team. When I look at this group of people who have as their life's mission the goal to find a treatment for NP-C disease as quickly as possible, I know that if we were on a playing field and our sport was football, we'd be National Champions. I am proud to be their coach.

To all of our supporters—donors, friends, sponsors, other NP-C families, volunteers and staff—I thank you sincerely for continuing to fight this urgent battle. *Together… we will be victorious.*

Sincerely,

Ara Parseghian

NP-C Scientific Conference

Tremendous progress has been made over the past fourteen years in terms of what has been discovered about Niemann-Pick Type C, the level of science being conducted, and—perhaps the most visible evidence—the sheer numbers of top scientists worldwide who are studying NP-C disease.

For the Parseghian Foundation's Scientific Advisory Board as well as the foundation staff and volunteers, it's been an uphill battle all the way. While keeping their heads down and their eyes focused on the goal, it's gratifying to receive validation that their efforts and results are lauded. Not gratifying in a selfish way, but in knowing that they are truly following a path that will lead to a treatment for NP-C children as quickly as possible…and that's what it's all about.

> *"We learned a great deal at the 2008 Scientific Conference. Your outstanding work is a model for other foundations that seek to find cures for rare genetic diseases."*
>
> **Drs. Michael Brown and Joseph Goldstein**

The quote you will see in the box to the left is from Drs. Michael Brown and Joseph Goldstein from UT Southwestern Medical Center following their participation in the 2008 Scientific Conference on Niemann-Pick Type C Disease sponsored and hosted by the APMRF. Having won the Nobel Prize for Science in 1985 for their pioneer work with cholesterol, these prestigious scientists are also very involved with NP-C disease research. Their validation of the efforts of the Parseghian Foundation is greatly appreciated.

Only three researchers attended the first NP-C Scientific Conference in 1995, and this was a majority of the scientists working on NP-C worldwide. More than 80 scientists from around the world attended the recent Conference, along with members of eight NP-C families.

(cont'd. on page 2)

University Medical Center Inspires Support

University Medical Center (UMC) in Tucson has helped make dreams possible for the Parseghian Foundation. Shortly after Michael, Marcia and Christa Parseghian were diagnosed with NP-C and the APMRF was established, Cindy Parseghian paid a visit to Greg Pivirotto, UMC President and CEO. Cindy and a volunteer committee had an idea to host a fundraiser in Tucson with UMC as the major sponsor. That fundraiser would become known as "One More Victory, Ara!" Celebrity Golf Tournament and Gala Weekend.

As Greg remembers, "One day Cindy came into my office and told me she had this idea and wanted UMC to be part of it. More significantly, Cindy said to me, 'I will not let my children die without a fight.' To that end, she was determined to raise money to further research. As she talked, I realized this was a natural fit—our research institution supporting a foundation whose goal was to find a treatment for a rare genetic disease. It is such a noble and worthwhile cause."

Since that conversation fourteen years ago, UMC has been the Title Sponsor of "One More Victory, Ara!" UMC's sponsorship has made this the largest annual fundraising event for the APMRF, and the second largest in the entire Tucson area. The event has netted more than $5 million for NP-C research over the years.

Another key individual at UMC who has given of herself in supporting UMC's involvement is Adaline Klemmedson, Vice President of Administrative and Corporate Relations. Adaline has been part of the original event committee and a long time friend of Cindy's. She feels strongly about UMC's involvement with the Parseghian foundation.

"UMC is an important leader in the community and we wanted to show the community that we are supporting this cause," she said.

Cindy Parseghian presents title sponsor gifts donated by Tiffany & Co. to Adaline Klemmedson and Greg Pivirotto.

Adaline herself is a community leader, involved in many organizations including United Way, The Arizona Medical Alliance Association and Angel Charity for Children. She further explains her personal involvement, "I was devastated when I heard the news of Cindy and Mike's children, so getting involved with the APMRF was the right thing to do at the right time to help a colleague and friend."

UMC's involvement as the major event sponsor has had a profound impact on the APMRF. This tremendous show of support from a nationally respected medical institution has brought visibility to the Foundation and credibility to the cause. As a result, many businesses and individuals in Tucson have come forward and become a part of "One More Victory, Ara!"

Our profound thanks to UMC, Greg and Adaline for their support of "One More Victory, Ara!" and their inspiring leadership in the battle against NP-C.

NP-C Scientific Conference

(cont'd. from page 1)

NP-C scientists discuss research informally over dinner.

The 2008 Conference was extended to three days allowing time for Drs. Brown and Goldstein to present their joint plenary talks, as well as to open up a block of three hours for open discussions amongst the scientists which proved to be both stimulating and informative. More than 35 scientific presentations were given in a spirit of collaboration.

The Scientific Advisory Board met to review 23 new research grant applications. Ten cutting edge projects were recommended for funding. Combined with the currently funded labs, this brings the total number to 25. Please visit the APMRF website at www.parseghian.org/currentlyfunded.html to view a list of the currently-funded researchers and their grant titles.

Our sincere thanks to all of our wonderful donors for making this Conference and grant funding possible. Because of your generosity we are speeding research toward a treatment so NP-C children can live to realize their hopes and dreams.

Heartfelt Thanks...

We are most appreciative of the many events and projects held across the US in support of the Parseghian Foundation in our battle against NP-C disease. Each dollar raised brings us closer and closer to a treatment. The following are a few vignettes about events that have taken place over the past several months:

When the check for nearly $5,000 was sent to the Parseghian Foundation from the **Lafayette (Indiana) Junior Women's Club**, Event Coordinator Trish Dowell wrote, "Our first annual **golf outing** to raise money for Niemann-Pick was a huge success and a day that all those involved will never forget. Anything our community can do to help the **Smith family** and all those dealing with this devastating disease is done with love and a true commitment to help in anyway, big or small." (Three of Trent and Julie Smith's four children were diagnosed with NP-C disease. They live in West Lafayette, IN.)

Keaton and Riley Smith…siblings *and* good buddies.

LONG REALTY Cares Foundation

The **Student Council of Catalina Foothills High School** in Tucson continued to celebrate the legacy of Marcia Parseghian by hosting the 4th annual **"One More Victory, Ara! 5K Walk/Fun Run"** on April 19 in her memory. Long Realty Cares was the presenting sponsor. Over the past four years the event has raised more than $70,000 for NP-C research.

"One More Victory, Ara!" Celebrity Weekend Presented by University Medical Center took place on April 25-26 in Tucson netting over $437,000. More than 900 attended the Gala and enjoyed the music of Vince Gill as well as singer-songwriters Don Schlitz and Al Anderson. We sincerely thank our title sponsor, **UMC**, as well as co-sponsors **Precision Toyota, The Jim Click Automotive Team, Bon Voyage Travel, Wells Fargo, La Encantada/ Westcor and The Westin La Paloma Resort & Spa.**

Country music superstar Vince Gill.

Adam Recke and his father Sean accept the check from the Spina Family.

The Race for Adam Foundation held their annual **5K Run Walk for a Cure** on June 14. This is one of many events organized each year by the family and friends of **Adam Recke**, an NP-C boy from **Bethlehem, PA**. Approximately 800 people came out to support the walk which raised a record amount this year thanks in part to a very generous, surprise $50,000 check given by the Spina family. The Reckes are one of many Niemann-Pick families who are dedicated to raising funds and awareness in the battle against NP-C disease.

Struggling with the first symptoms of NP-C disease is difficult at any age, but especially for a teenager. When you have the love and support of family and lots of friends, it sure helps. **Andy Wood** who has NP-C and is from **Derry, NH** has experienced first-hand how much he is loved. When he graduated from high school in May he received a standing ovation from his several hundred classmates and their families. Two weeks later more than 100

Andy Wood hugs friend Michelle Simms.

Ara Parseghian Medical Research Foundation

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Peter Schivarelli and........................

The legendary rock group Chicago and their manager, Peter Schivarelli, have consistently raised significant money for the battle against NP-C disease.

In 1995, Chicago organized a benefit concert at Notre Dame, shortly after Michael, Marcia and Christa Parseghian were diagnosed, and the APMRF was launched. More than $100,000 were raised from this one concert…giving a huge boost to the research that could be funded.

Ever since, the band has donated a portion of their tickets sales from concert tours raising more than $600,000. Peter tells of their dedication, "I told Ara we would be involved from the beginning." They have kept their word.

He continued, "I think we have brought a certain awareness to NP-C as all of our concert advertising states that a portion of the sales goes to the Parseghian Foundation."

There is a personal side to the band's involvement: Peter played football for Coach Ara Parseghian forty-one years ago. Ara gave Peter, who was an unheralded walk-on, a coveted spot on his talent-rich Notre Dame football roster. Peter Schivarelli never forgot the kind gesture.

So, when he learned that Ara's grandchildren had a rare genetic disorder, Schivarelli didn't hesitate to help his former mentor. "Ara had the biggest influence in my life: playing football for him changed things for me," said Peter.

In 1974, after Peter became involved with Chicago, he brought the band onto the sidelines to watch the Notre Dame/Southern California game with Ara's permission. More than 20 years later while riding on their tour bus, the group read a copy of *People* magazine with the article about the Parseghian family and NP-C. They all agreed immediately that they would do what they could to help. Peter has also contributed substantially on a personal level.

Chicago performed at the "One More Victory, Ara!" Gala in 2001. Our sincere thanks to Peter and the members of the band for their incredible love and generosity.

Angel Twins

The Bouchard Family – Justin holding Corynne, Colin, Caleb, Kristen with Cathryn

Excerpted by permission from a story written by Laurie M. Wirth/Special Contributor to The Dallas Morning News titled "Frisco family tries to raise hope against deadly disease." June 11, 2008

At first glance, Cathryn Bouchard is like any other toddler. She enjoys playing peek-a-boo with her brothers and spending time with her daddy when he gets home from work.

But Cathryn was born with a rare disease known as Niemann-Pick Type C, a debilitating illness that is always fatal. Her twin sister, Corynne, recently died of the disease, a few months short of her second birthday.

The girls' parents, Kristen and Justin Bouchard of Frisco, recently launched a campaign to raise $1 million to find treatments and a cure for NP-C, as well as raise awareness about the disease. Since March, they have raised nearly $11,000. (As of September 1st they have raised $44,000.)

The fundraising goal seems daunting, but Mrs. Bouchard says if 100,000 people donate $10, the family would meet its goal.

I thought, "What do I feel can make an impact or leave a legacy for my sweet little girls?" she said. "My girls are worth more than a million dollars. It seemed like that was achievable."

Typically, the disorder is identified in children ages 4 to 10, but doctors diagnosed Cathryn and Corynne after their first birthday, Mrs. Bouchard said. The twins had enlarged livers and spleens, and a computer search of those symptoms brought up NP-C as the first match.

"I just started bawling at the computer," she said. "I said, 'This sounds like my kids.' It was one of those mother's gut instinct type of things."

An outpouring of love and support has given the family the strength to keep working toward its goal to help children with NP-C, Mrs. Bouchard said.

"We feel like perhaps there's some kind of purpose," she said. "If not a cure, then treatment to prolong their life and make it more enjoyable."

Justin and Kristen Bouchard created the Million Dollar Mission to raise funds for NP-C research and education. Proceeds go to the Ara Parseghian Medical Research Foundation.

Corynne and Cathryn Bouchard

In Memory

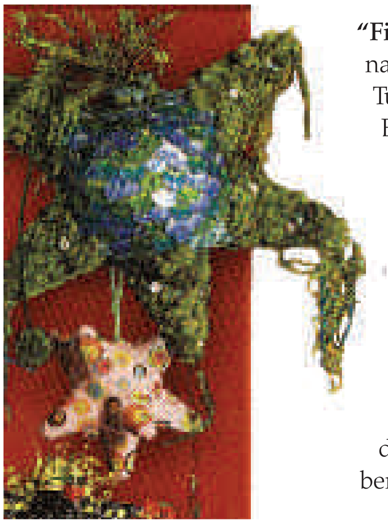
Sadly, since this story was written Cathryn has joined Corynne in heaven. They truly are little twin angels now. Our hearts and love go out to the Bouchard Family.

bowlers, including many from his youth group at North Salem Methodist Church, turned out for **"Project Andy Bowl-a-thon"** raising more than $10,000. Our thanks to everyone who supported Andy and all those afflicted with NP-C disease.

For many years the **Pebble Beach Coaches Classic** in **Northern California** has designated the Parseghian Foundation to be the beneficiary of their annual charity golf tournament. Coaches from around the country bring a foursome to play in the golf tournament. Many of the players make donations to the APMRF. We are very grateful to these thoughtful individuals.

Melinda Johnson, a kindergarten teacher at **Washington Henry Elementary School** in **Mechanicsville, VA** has the heart of gold…and a very special place in her heart for one precious student, **Ashton Friedl**. Melinda rallied her class as well as students and teachers from the entire school to participate in a walk-a-thon in support of Ashton, who has NP-C disease. The **Walk for Ashton** is evidence of Washington Henry's school motto: "The Heart of the Community." Not only were $15,000 dollars for research raised…but so were the hopes and spirits of the Friedl family who expressed their appreciation to everyone involved.


Ashton Friedl participates in the Walk with her dear teacher, Melinda Johnson.



"Fiesta Fantastica" is certainly an appropriate name for the fun event held on May 9 at Tucson's premier shopping center, La Encantada. More than 500 Tucsonans enjoyed the evening festivities including delicious food and beverages donated by area restaurants and resorts, colorful decorations, lively music and dance. The event was presented by **Chapman Automotive** and sponsored by *Tucson Lifestyle Home & Garden* along with **La Encantada**. Local artisans decorated more than 70 colorful piñatas, which were displayed and sold during the evening to benefit the APMRF.

Mark Your Calendar

September 27, 2008 - The 10th annual **Leoni Family "Fight For Jessica" Benefit** at The Manhattan Beach Marriott in **Southern California**. To commemorate ten years their special theme will be "Decade of Devotion." The evening benefits the APMRF and includes dinner, a silent auction and a special program. Visit their website at www.fightforjessica.com.

September 28, 2008 – Hosted by the **Smith Family** in honor of their three children with NP-C, **"BReaK Thru Fund Golf Outing"** will be held on September 28 at Lafayette Elks Country Club in Lafayette, IN. Call Trent Smith for information: (765) 477-3410.

October 26, 2008 – Enjoy wonderful food in a beautiful atmosphere at Tucson Culinary Festival's **"Sunday Brunch & Copper Chef Challenge"** to benefit the APMRF. Held at Loews Ventana Canyon Resort in **Tucson**. Call (520) 577-5106 for information.

January 24, 2009 - **Verna and Roy Burrows**, grandparents of an NP-C child, and their friends in **Las Vegas** are hosting their 4th annual **"Touchdown for Ty"**. This family-oriented variety program will feature musical and dance acts, as well as a reception and silent auction. Call the Burrows at: (702) 363-5443.

April 17-18, 2009 - The 14th 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.