

# A GOAL FOR LIFE

For Friends and Supporters of the Ara Parseghian Medical Research Foundation



*"It is hope that gives life meaning.  
And hope is based on the prospect of  
being able one day to turn the actual world  
into a possible one that looks better."*

*—Francois Jacob,  
French Biologist and winner of the 1965 Nobel Peace Prize in Medicine*

*May the Holiday Season fill your home with the  
Spirit of Love, the Courage of Hope, and the  
Blessings of Peace.*

*With Warmest Wishes,  
The Parseghian Family*



## New Drug Trial Begins!

A Phase I proof-of-concept trial with a histone deacetylase inhibitor (HDACi) began in September at the National Institutes of Health (NIH) Clinical Center to help determine if this class of drugs may be beneficial for treatment of NPC1 disease. The initial HDACi drug being tested is vorinostat. Vorinostat has already been approved by the FDA for the treatment of cutaneous T-cell lymphoma.

A NIH Institutional Review Board approved a protocol of vorinostat in a cohort of 12 adult NPC1 patients. To date, three patients have enrolled in the trial. This trial is focusing on the safety of HDACi in NPC1 patients and to determine if HDAC inhibition has a desirable biochemical effect in white blood cells of NPC1 patients. Since this is a proof-of-concept trial and the safety of this drug in NPC1 subjects is not likely to differ significantly from patients with cutaneous T-cell lymphoma, the APMRF was able to obtain a waiver of the requirement for an Investigational New Drug application for the testing of vorinostat in adult subjects with NPC1.

Merck Pharmaceuticals has graciously donated the vorinostat for the trial. Paul Helquist and Olaf Wiest at the University of Notre Dame first recognized the potential therapeutic affects of HDACi. The Maxfield and Sturley research groups showed that HDACi are able to reduce cholesterol storage in cells that have been cultured from NPC1 patients. Drs. Ory, Maxfield, and Porter were awarded a National Institutes of Health (NIH) U01 grant to evaluate HDACi in NPC1. This was one of the first

grants of this nature awarded by the NIH to promote extramural utilization of the NIH Clinical Center.

An "HDACi Working Group" has been collaborating over the past year to test the utility of the HDACi in animal models and to establish the clinical trial of HDAC inhibition in NPC1. This intramural/extramural collaboration includes investigators from Washington University (Dr. Ory), Weill-Cornell (Dr. Maxfield), Notre Dame (Drs. Helquist and Wiest), NIH (Drs. Porter and Xu), Broad Institute (Dr. Holson), TD2 (Dr. Steven Gately), and Cindy Parseghian, President of the APMRF. The Notre Dame College of Science and the Ara Parseghian Medical Research Foundation are supporting this effort.



Members of the HDACi Working Group at recent meeting

## Give the Gift of Life

Looking for the perfect holiday gift idea?

In this season of giving please consider a tribute to a family member, friend or client to the Parseghian Foundation. When you make a donation (whether honor or memorial), a card advising of your gift will be sent to the person(s) you indicate.

Would you like to double your gift? Check with your employer to see if they provide a matching gift program.

Call APMRF at (520) 577-5106, make a donation online at [www.parseghian.org](http://www.parseghian.org) or use the enclosed envelope. Thank you!





# Heartfelt Thanks...

## The Band Chicago forever bringing hope to NP-C families...

This past August, Jay Patrick "JP" Honsinger, an 11 year old with NP-C disease, had an evening to remember. Through the continued generosity of the band Chicago, JP, his family, friends and a few other NP-C families were guests of the band at their concert at the Saratoga Performing Arts Center (SPAC) in upstate New York.

The evening began with a gracious greeting by the entire band and was followed by a fabulous concert by Chicago and REO Speedwagon.

Chicago Manager, Peter Schivarelli who played for Coach Ara Parseghian at the University of Notre Dame, has never forgotten the influence that Ara had on his life. He promised when the Parseghian children were first diagnosed with NP-C to be involved with the fight for a cure. Since that time, Peter and the band have raised over \$1,250,000 by donating a portion of their ticket sales from concert tours, along with playing at various APMRF fundraisers. In addition to the band's financial contributions, they are also committed to bringing hope to NP-C families through their personal interactions with the children and their families.

We wish to thank the Partlow family for coordinating this effort, the folks at SPAC and to the band Chicago who never cease to amaze and continue to colour our world.



*JP Honsinger with band member, James Pankow*



*The band Chicago with the Honsinger family and friends*

## The Million for Tucson – Jim Click Jeep Cherokee Raffle



*Jim Click selecting the winning ticket at a celebration with the participating Tucson charities*

Jim Click, owner of Jim Click Automotive, is well known in Tucson for his dedication to helping local charities raise millions of dollars through his annual car raffles. Over 300 local charities participated in the most recent Jeep Cherokee raffle. The Parseghian Foundation had a huge response and was pleased to sell over 1,500 tickets, netting more than \$32,000 bringing the total from all five Jim Click car raffles to \$150,000. We sincerely thank Jim and his family for their ongoing support and generosity. Their commitment to the Foundation, which extends far beyond the car raffles, exemplifies the vision that makes them a vital part of the Tucson community. Winners of the Parseghian Foundation drawing are listed on our website ([www.parseghian.org](http://www.parseghian.org)). Thank you to everyone who participated!

## Tucson Orthopaedic Institute

We wish to extend our appreciation to the Employee Wellness & Activity Committee (EWAC) at the Tucson Orthopaedic Institute for their fundraising efforts on behalf of the Foundation. Recently, they sold chocolate and sent the proceeds to the Foundation... so sweet! Each and every year the employees at TOI dedicate time and effort to support NP-C research.



## Summer Concert in Honor of Ashton Friedl

We wish to extend our sincere thanks to Julie Gordon, cousin of 12 year old Ashton Friedl, who coordinated an event at the Westchester Commons in Midlothian, VA this past August. As a part of the Westchester Concert Series, the Sedona Taphouse Craft Beer Fest held a fundraiser benefiting the Foundation while raising awareness of NP-C disease. Thank you to all who supported this event.



*Ashton Friedl at the Summer Concert*

## Ocran United Methodist Helping Hands

In September, the Ocran United Methodist Men were cooking it up once again in honor of Ashton Friedl. They barbequed 900 chicken halves and combined it with some delicious, traditional side dishes. The Day Circle of the Ocran United Methodist Women topped it off with some amazing homemade pies, cakes and cookies. This pairing of the two organizations raised \$6500 in honor of Ashton and in support of NP-C research. We give thanks to this dedicated group for their ongoing support.

## Dedication...Boler-Parseghian Center for Rare & Neglected Diseases

Established in 2009, The Notre Dame Center for Rare & Neglected Diseases was recently named and dedicated to two families with longtime ties to the University of Notre Dame – The Boler Family and the Parseghian Family. The Boler family made a generous gift to ND to endow the Center and chose to name it in honor of their parents John and Mary Jo Boler and Michael, Marcia and Christa Parseghian, the children of Mike and Cindy Parseghian.

Through a generous gift to endow this Center the Boler family stated: "Our parents always demonstrated to us that in order to take on the most difficult challenges, we need to view them as opportunities for hope and change. We are honored to be able to join with the Parseghians and the University in this fight for those who often feel they have little reason for hope due to a lack of cures and therapies for rare and neglected diseases. This is a tremendous challenge, and our family can think of no better way to honor our parents."

In response to this great honor Mike & Cindy Parseghian shared, "The Notre Dame community has embraced our family as we struggled with the loss of our three children." "Notre Dame is unique in its mission to serve the disadvantaged, including the millions who struggle with rare and neglected diseases. We are blessed to be part of this great community."

The focus of the center is to find cures and therapies for rare and neglected diseases and the center embraces a wide array of researchers who work to develop life-saving treatments for any illness that affects fewer than 200,000 people.

Notre Dame's center is composed of researchers from the College of Science departments, such as biological sciences, chemistry and biochemistry, that have researchers with experience in vaccine development and medical chemistry; from the College of Engineering departments with expertise in drug delivery platforms; as well as faculty from the College of Arts and Letters and Center for Social Concerns who are involved in outreach to patient communities and social development programs.



*Boler-Parseghian Dedication*

# Mark Your Calendar

## March 12, 2015

The University of Arizona Rugby Team will host the third annual "One More Victory, Ara Parseghian Cup", a rugby series between the University of Notre Dame and the University of Arizona, dedicated to raising money for NP-C research. This game will be played at the William David Sitton Field in Tucson, named in memory of Dave Sitton, UA Rugby coach and longtime friend of the Parseghian family and foundation.

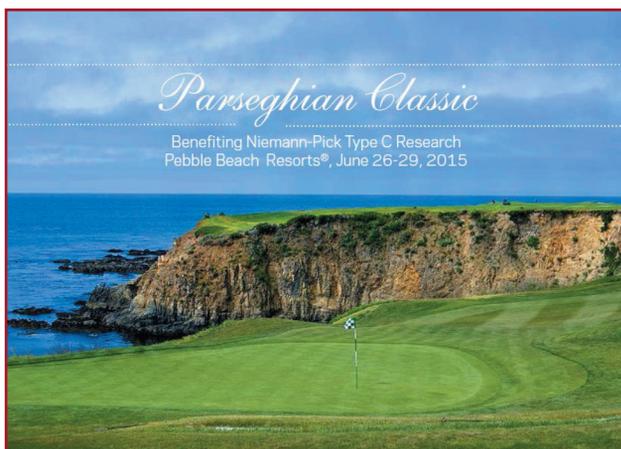


## May 26- June 26, 2015

Greg Crawford, Dean of the College of Science at Notre Dame, will once again ride his bike cross the United States for the lives of NP-C children, continuing his quest to raise awareness and funds to support NP-C research. Greg will ride from Friars Head, Long Island to Pebble Beach, California, where he will be welcomed by the Parseghian Classic guests (see below). Along his route, Greg will meet with NP-C families and Notre Dame Clubs. To follow Greg's journey go to: <http://blogs.nd.edu/gregcrawford/>

## June 11-13, 2015

The annual "Michael, Marcia & Christa Parseghian Scientific Conference" for Niemann Pick Type C research will be held on June 11 -13, 2015 at the University of Notre Dame. Researchers will gather for three days to discuss the advances in NP-C research. This yearly meeting helps to form collaborations and determine the future direction of NP-C research. Dr. Christopher Austin, Director of the NIH National Center for Advancing Translational Sciences, will be the keynote speaker.



## June 26-29, 2015

The fourth annual "Parseghian Classic", a 3 day golf tournament, will be held at the beautiful Pebble Beach Golf Resort. Golfers will play a round of golf at Spyglass Hill Golf Course and another at Pebble Beach Golf Links. The all-inclusive event includes a welcome reception and dinner, a putting tournament, and a final reception and dinner with a special guest performance. Full golf and non-golf packages are available. Contact [promano@parseghian.org](mailto:promano@parseghian.org) for more information.



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### *A Letter from Chase & Dillon*



Chase and Dillon, grandsons of longtime friends and supporters of the Foundation, Bill & Lynda Ford, recently sent this letter accompanied by a donation. Our hearts are touched by the generosity of spirit in those so young. Thank you.

