ROAD TO DISCOVERY 2012

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UNIVERSITY OF NOTRE DAME College of Science

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NOTRE DAME FEDERAL CREDIT UNION
Riding for the Lives of Children

3,250 Miles
33 Days
13 States
2 Wheels
1 Goal
A goal for a cure

Road to Discovery

Photo Credit: Peter Doran Photography, www.pdoranphoto.com
University of Notre Dame dean of the College of Science, Greg Crawford, cycled 3,250 miles from Boston, Mass., to Pebble Beach, Calif., to raise awareness and funds for research to find a cure for Niemann-Pick Type C (NPC) disease. His third cross-country ride started on May 21 and concluded on June 22, in time for the Parseghian Classic, a golf fundraiser at Pebble Beach Resorts.

The Road to Discovery 2012 bicycle ride demonstrates Notre Dame’s commitment to research to find a cure or treatments for the devastating neurodegenerative disease that has taken the lives of too many children, including three grandchildren of coach Ara Parseghian.
Niemann-Pick Type C (NPC) is a rare and deadly neurodegenerative disease that primarily strikes children before or during adolescence. An inherited cholesterol metabolism disorder, NPC strikes one in every 150,000 children.

The National Institute of Health refers to NPC as “childhood Alzheimer’s” because of similarities in the brains of NPC and Alzheimer’s disease patients. Symptoms can include deterioration of memory and balance, lung and liver failure, delayed motor development, and seizures. The disease usually appears in early childhood, leading to neurological problems that are fatal.

In a message to all who want to find a cure, Coach Ara Parseghian said, “I am asking for your support and that of your family and friends as we commit to victory against Niemann-Pick Type C, the neurodegenerative disease that has claimed the lives of my three youngest grandchildren.”

“Cowboy Michael lost his battle to NPC in 1997 at age 9. Sweet Christa passed away in 2001 at the age of 10. Our precious Marcia died in 2005 at the age of 16. We miss them so much.”

Since its inception in 1994, the Ara Parseghian Medical Foundation has funded more than 60 labs, made strides in discovering a cure for the disease, and formed a partnership with the University of Notre Dame. With the goal of saving lives, this partnership will raise funds to support NPC research at Notre Dame and with collaborators around the world.

As a result of the partnership, Notre Dame researchers established the Drug Discovery Core, to which any member of the worldwide NPC research community may turn for the design and synthesis of potential drug candidates. Since then, a team of researcher-collaborators from Notre Dame and Cornell uncovered evidence that histone deacetylase inhibitors correct NPC’s genetic flaw, which is one step closer in our goal of finding a cure.

Looking back, we find it hard to believe that it has been 18 years since our children were diagnosed with NPC; while sometimes it seems like a lifetime, often it feels like only yesterday. And though Michael, Christa, and Marcia are no longer with us, we can still hear their laughter, see their sparkling eyes, and feel their little arms hugging us. While we miss them unbearably, they inspired a legacy of hope.

—Cindy Parseghian

niemannpick.nd.edu
THE RIDE
3,250 Miles

Greg Crawford, dean of the College of Science at the University of Notre Dame, wrote the following blog entries each day of the 3,250-mile bicycle ride from Boston, Mass. to Pebble Beach, Calif.
Today was a nice ride—temperatures in the mid-60s and, believe it or not, a tailwind most of the way. We had a little misty rain, but overall the day was very pleasant. This was the shortest leg of the whole ride—only 75 miles. Passing through Boston was a somewhat surreal experience—it was Boston College’s graduation day, and we were zipping through all that traffic with our Notre Dame van and our jerseys on full display. I was a bit nervous, and we did catch some beeps and bleeps, but we made it through Eagle country without incident and rode to Sturbridge, Mass., which is right on the Connecticut state line.

What made today really special was having Ara Parseghian, coach Parseghian’s grandson and namesake, on the ride with me for the first 20 miles. Ara just graduated from Tufts University School of Medicine, so his mom and dad, Cindy and Mike, happened to be in town to help send us off. As a symbol of the start of the cross-country ride, we dipped our rear tires into the Atlantic—and then on the day we arrive in Pebble Beach, I will dip my front tire into the Pacific. The water level was so low that we had to hang on to each other as we leaned over the side!

Right after we arrived in Sturbridge, I had a meeting with John DelliSanti, president of Carestream Health, in Connecticut. Notre Dame has collaborated with Carestream in the area of molecular imaging. John and I talked about molecular imaging, entrepreneurship, and intellectual property. When we walked out to the parking lot, we found an 8-year-old boy admiring the van. His mom told us his goal is to come to Notre Dame—Class of 2026. He signed the van and was so happy with the Notre Dame T-shirt we gave him. He told us his birthday is coming up in two weeks, so he will count the shirt as a birthday present.

Tonight we had an event with the Notre Dame Club of Hartford at Bellini’s Restaurant, just outside of Hartford. It was a great night. The club members from Hartford were wonderful and gave us a really warm welcome. The club is actively engaged and very informed about the cause, and they have been reading the blog. Kristin, a Notre Dame undergraduate studying accounting, joined us with her parents. We handed out T-shirts, and of course everyone signed the van.

Thank you, Hartford Club, for welcoming us to your city. We had a great time. Thank you, Jim, for organizing the event.
Last year, when the Notre Dame women’s Irish basketball team played Texas A&M, I saw the Aggie coach doing something I really liked. Right before the game started, coach Gary Blair walked over to the media bench, picked up a magic marker, and wrote a plus sign on his hand. Someone asked why, and he answered that the symbol reminds him always to be positive. I thought this was a great idea, so I had some yellow bracelets made for myself with lots of ++++++++ (plus signs) and the words “Be Positive” engraved on them.

I was glad to have those “be positive” reminders today. It was raining and I knew that the rolling hills were going to be challenging. I wore my yellow band outside of my coat to remind myself to stay positive every time I glanced at my wrist.

The hills we rode were gorgeous. The rain showers were refreshing and kept me cool; the water running over the road reminded me of a glass half full. The mud didn’t taste that bad, and the dog chasing me was friendly. There were plenty of reasons to be positive today.

On top of a great ride, I have the support from the University and the Ara Parseghian Medical Research Foundation to do something that most people only dream of—ride a bike across the country for a wonderful cause. I am very grateful to have the opportunity to participate in a cause we are all passionate about at Notre Dame.

One of the best parts of this ride is to meet with those who love Notre Dame. Tonight we visited the Notre Dame Club of the Mid-Hudson Valley in Poughkeepsie, N.Y. We went on tour of the bridge over the Hudson River, which was converted from an old railroad bridge into a spectacular crossing for pedestrians and bicyclists.

After our tour, we had dinner at Cosimos. The club welcomed us and also gave me a chance to speak to them about Niemann-Pick disease. The group also presented me with a great polo shirt from the Mid-Hudson Valley Club. Thank you to the club for your kind hospitality. I would like to especially thank Les and Linda for organizing a great event.

So, it was a wonderful day! I think I’ll have another wonderful day tomorrow, too.
Today we had a little bit of everything—rain, including heavy cold rain in the Catskill Mountains, and then beautiful sunshine for the last third of the day. The brightest part was finding out that there really are Irish fans everywhere.

In Ancramdale, N.Y., a village with a population of about 1,500, Les, the former Hudson Valley Club president, greeted us with a pickup truck outfitted with a Fighting Irish flag. Thanks, Les—it was great to see you, and thank you again, both you and Linda, for a wonderful evening yesterday. The Notre Dame Club of the Mid-Hudson Valley Club is awesome.

The hilly ups and downs on the road today were pretty ordinary, but the countryside around us was unbelievably gorgeous. In spite of the pockets of rain, we had a great day. We’re looking forward to the ride to Corning tomorrow.

In Walton, we’re staying at the Octagon Motor Lodge, across the street from one of only eight brick octagon houses in the country. The Motor Lodge owners, Maryanne, Stubby, and Grandma (who raised 10 children!), came out to greet us in the parking lot when we arrived. They loved the van and signed it by drawing a big octagon in New York on the back. The lodge, built in 1855 and bricked in 1875, is a major landmark here in the Catskills along the Delaware River. Our hosts are terrific people. Maryanne told us that Stubby got his nickname from his stubbornness!

A beautiful, restful evening just 2½ hours (by car) from New York City.

May 23, 2012
I am very grateful to have the opportunity to participate in a cause we are all passionate about at Notre Dame.

–Dean Greg Crawford
Today we crossed from Pennsylvania into Ohio, the northeast part of the state where I grew up and went to college. We picked up a Notre Dame rider today in Ohio—Tom, a chemistry alumnus, and his 14-year-old son, Jamie. They rode with us for 17 miles. Along the way we saw this gigantic Trojan Horse, about 40 feet tall and made of wood, that would have made a USC fan envious.

When we got to my parents’ home in Elyria, the same house where I grew up, my mom and dad, Dolores and Phil, greeted us with my sister Karen and cousin Peggy. Mom was ready for the old routine—I brought plenty of laundry! We had a barbecue in Bay Village in the evening with Steve, a science alumnus, and his son Ben, who played baseball while he was at Notre Dame. It was great to see people in this area who are passionate about the University. There were also four people at the barbecue from Kent State, my alma mater.
This Memorial Day was a day to focus for me—to focus on the biking against probably the strongest crosswind and headwind I’ve ever faced, and to focus on remembering the brave men and women who have gone before us. We had a beautiful start in the early morning with a gorgeous Ohio sunrise, and the sun just kept getting hotter all day. The strong wind was whipping the numerous Memorial Day flags in a way that really got your attention along the whole route, more than 150 miles. The bike ride stopped in Holiday City, a little village in far northwestern Ohio. I drove into Toledo for an interview with ABC News about Niemann-Pick, and why we’re doing this ride.

Memorial Day is a day for remembering the soldiers who have fought to keep us safe and free, and the flags that stood out in the wind were an inspiration to keep that in mind all day. With my head down against that wind much of the time, I found myself also remembering the brave boys and girls that have fought Niemann-Pick—the Parseghian children, whose memory constantly inspires us, and also the beautiful children we met last year on the ride, along with their brave and generous families who are our partners in this fight. Every one of them is an inspiration to keep up this battle, no matter the challenges, until we have reached the victory—the cure.
Today was a terrific day for riding and reaching home for a visit. Peter, a math professor from Notre Dame, and Tom, a friend from Knollwood Country Club, joined us on the sunny, breezy ride from northwestern Ohio.

When we reached Granger, we stopped off at coach Ara Parseghian’s house, so he could sign the van.

Coach joined us tonight for a well-attended Mass and reception at the Jordan Hall of Science, where he gave another inspiring talk about how the Ara Parseghian Medical Research Foundation got started. It was within about a week after Mike and Cindy told him that three of the grandchildren had been diagnosed with the fatal, mysterious Niemann-Pick Type C disease. No matter how many times I hear that story, it’s always inspiring, and I love the way Coach Ara describes the progress: we were on our own 1-yard-line. We’ve gone so far down the field that we’re already extending the lives of children and making other advances, and we need to take it over that goal line. He was very generous when he talked about my more recent arrival on the team and how he’s confident that we can find the solution. My great-uncle played football for Knute Rockne, and I like to think that I’m on Coach Ara’s team to win this championship. It meant so much when he talked about what I can do to help as a scientist, a fundraiser and a bike rider.

This day was also dedicated to Audrey Gogola, the daughter of Tracy Vargo-Gogola, an adjunct assistant professor in Biological Sciences who does breast cancer research in the Harper Cancer Research Institute, and her husband, Mike. Audrey died recently at age 3 from complications related to a genetic illness. The Audrey Gogola Scholarship Fund has been established in her memory to help worthy medical students.

At the reception, our partner in the ride, Notre Dame Federal Credit Union, announced some new ways to help raise money for research. We also honored Patrick, Peter, and Nick, the guys from Destination Cycling who do the behind-the-scenes work that keeps us going down the road. We’ll head out to Chicago on Wednesday with a fresh boost of energy from our time on campus.
“We face our headwinds, our rocky roads, our steep uphill climbs, and sometimes we get to see how much progress we have made and gain confidence that we are going to make it to the goal.”

—Dean Greg Crawford
After a great night’s sleep in my own bed, we left from Granger at 6:00 a.m. Renate made a fantastic breakfast for us before we took off. We were surprised to see Captain Carter from the University of Notre Dame Naval ROTC stop by the house bright and early with his two kids. The kids had made signs, which I brought with me in the van. I also had the chance to ride my bamboo bike from Zambikes this morning.

The ride to Chicago was pleasant—windy and cool, but uneventful, which was fine because we had plenty to do in the city.

We visited with the Chicago Red Stars professional women’s soccer team, which includes many former Irish players. It was great to see the team—they gave us a terrific welcome, and all signed the van. Having teenage daughters myself, I really think these women soccer players are great role models for young girls in athletics. It was a pleasure to meet them all and see such a big ND group playing in Chicago. After the ride, I will come up to catch a few games. I am so excited to see them play later this summer.

We also stopped in at SRAM to see Jeff, a Notre Dame alumnus who has been with the company since it started. SRAM makes biking components, from shifters to sprockets to carbon fiber rims. My bike is outfitted with all SRAM parts.

We took a tour of all the great innovation going on at the company while my bike was getting a needed tune-up after 1,000 miles on the road. SRAM took good care of me. After the tune-up, the bike is running perfectly.

This evening, Brad and Al organized a dinner with two of my science advisory council members, Sam ’74; Denis ’67; and Phil ’74. We had a great meal at Mon Ami Gabi and wonderful conversation. Everyone signed the van.

What a great day today!
Part of an old Irish blessing, "May the wind always be at your back," is written on the side of our van, and today it certainly came true. It was cold—never much above 50 degrees—and we ran into cold rain for the last 10 miles, but the strong tailwind helped us make great time.

Jeff from SRAM, who helped with the components and tune-up that I mentioned in yesterday’s blog, accompanied us today, which was great fun. Jeff has been incredibly supportive of the ride, and it’s wonderful to have such engaged alumni. Thank you, Jeff, for your support.

We enjoyed the beauty of northern Illinois nature, especially farmland, on our wind-driven ride that was mostly along pleasant bike routes. Arriving early in Mendota gave me a chance to catch up on emails, phone calls, and work, as well as some much-needed rest. I certainly need the rest as the forecast says we’ll be heading into the wind again tomorrow.
Exciting news for the College of Science!

From out here on the Road to Discovery, I am delighted to announce a very special gift that will have a significant, long-lasting impact on the College of Science, the University of Notre Dame, and the lives of countless people suffering from disease.

We are overwhelmed with gratitude for the generous gift from Mike and Liz Gallagher: three endowed professorships to support adult stem cell research at the University of Notre Dame. These three professorships in the College of Science will be called the Elizabeth and Michael Gallagher Family Professorship in Adult Stem Cell Research.

As you may know, adult stem cell research has the potential to accelerate the discovery of new and successful treatments for diseases such as Type 1 diabetes, Parkinson’s disease, cardiovascular disease, macular degeneration, spinal cord injuries, and even Niemann-Pick Type C. At Notre Dame, our research focuses on adult and all forms of non-embryonic stem cell research. With these new endowed professorships, Notre Dame will be in the forefront of discovery through adult stem cell research, aimed at unlocking the mystery of these many diseases and finding the cure.

The impact of this gift is truly beyond measure. It will play a crucial role in attracting three more of the best minds in the field of adult stem cell research to Notre Dame. Furthermore, this gift will equip our existing talented group of adult stem cell researchers at Notre Dame to take the next great leap toward ultimately forming a premier center in adult stem cell research.

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Thank you, Mike and Liz Gallagher, for your very generous gift that should have a large impact on the research environment at Notre Dame.

David Hyde, director of the Center for Zebrafish Research at Notre Dame, on June 4, 2012

Today was also a great day on the road, in spite of a headwind. We picked up an extra rider for the trip—Sara from Development at Notre Dame, who grew up in Davenport. We rode down the wonderful bike trail hugging the Mississippi River on the Illinois side and then crossed into Iowa over the Centennial Bridge. Davenport is a beautiful city, and the Notre Dame alumni gave us a warm welcome tonight. Scott, the club president, organized a great event for us. The club members all came out to sign the van. We were also joined by partners from the Notre Dame Federal Credit Union, which is sponsoring the ride and working with us on innovative ways to raise more funds for the cause.

What a wonderful evening in Davenport, and what a memorable day thanks to the transformational gift of Mike and Liz!
The wind was already pretty strong when we left Davenport this morning on some very smooth and beautiful bike trails. About 10 miles out, we committed ourselves to a route where the map indicated a few rocky and dirt roads. We figured the rocks and dirt would be minimal. They weren’t. We found ourselves stuck out in the middle of nowhere on roads that were not made for road bikes. And the crosswind had gotten stronger. And it started to rain. The combination of road and weather made for a difficult biking day.

Even in such a desolate spot, we found evidence that Irish fans are everywhere. We went for hours on those back roads without seeing any other people or vehicles at all. Sean, from Development, was driving the van. At last, a large farm sprayer approached, and the driver, Steve, jumped out to introduce himself. It turns out that Steve’s daughter is a freshman at Notre Dame!

Before we said goodbye, he gave us a donation for the NPC cause. What a wonderful bright spot in the middle of a difficult day.

Finally, as we rolled into Iowa City, the sun came out. We just sat and soaked up the warm light before we went into the hotel. That evening, the Notre Dame Club of Iowa City had arranged for us to enjoy their city’s arts festival with exhibits and a band right downtown. The festival was pleasant, and the weather was beautiful—a perfect ending to a day with such a “rocky” start. Tomorrow, we’re looking forward to a long ride to Des Moines and another alumni club event.
“Notre Dame is with us at every turn on the Road to Discovery. It keeps me pedaling to reach the next exciting opportunity.”

–Dean Greg Crawford
Iowa looks flat when you drive through the state in a car, as I have several times, but when you’re on a bike, you realize there are a lot of rolling hills.

Today was a pedaling workout, but the weather was gorgeous and a little breezy nothing like the tough conditions we faced yesterday.

I managed to work up quite an appetite from all the exercise. The Notre Dame Club of Des Moines had a barbecue for us, and I ate four hamburgers and many servings of banana pudding! The setting was beautiful; the food was delicious; and the company was even better.

We had a great turnout with alumni, incoming students, current students, College of Science graduates, and more. We told many great Notre Dame stories, and everyone signed the van. My new buddy, Lucas, sported the official Road to Discovery riding jersey.

On to Nebraska tomorrow!
Today we enjoyed the last day of the beauty of Iowa; the countryside was just spectacular. It was hot and windy again, and for most of the ride the crosswind was challenging. We crossed the Missouri River late in the day and rolled into Nebraska. Overall, it was a nice day on the road.

We were joined at our hotel outside of Omaha by Jim, one of my advisory council members, and his wife, Ann. They are so supportive of my rides. Last year, they even met us when we ended in Dallas. This evening, we had a wonderful dinner at Jean and Ron’s house in Omaha, and the Notre Dame Club of Omaha president, Ed, joined us. They gave each of us Nebraska Cornhusker shirts, just in case we might need them in the next few days.

This evening was a great ending to a wonderful day. The ride is extra long tomorrow, so we’ll get started bright and early at 5:00 a.m.
Today was just about perfect—sunny, light wind sort of at our backs, and not a cloud in the sky. We had many rolling hills heading west out of Omaha, but then it turned pretty flat. In fact, it is not really flat, although it looks flat, but there seems to be a constant 1% rise in altitude—they say that this will be the case all the way to Denver.

The van got a lot of attention today from drivers, truckers, and hotel employees. Lots of people who saw us on the road gave us beeps and waves, and the ABC Lincoln reporter who came out to interview me loved it.

My science advisory council member, Jim, and his wife, Ann, came to York today after visiting us in Omaha, specifically to take us all out to dinner at the well-known steak restaurant called Chances “R.” My steak was amazing! Nebraska steak cannot be beat!

Thank you, Jim and Ann, for everything you do for the college and Notre Dame, and for taking the time to visit us in Nebraska!

Great job, Greg. Very proud of you. Very many people are helped through your enthusiasm and great effort. Good luck for the rest of your trip.

Anneke De Boer on June 5, 2012
Today was another beautiful day – nearly 120 miles on the road, and except for a crosswind, the weather was exceptional. I have been impressed by the large grain fields in Nebraska; they are gigantic. The land is planted as far as the eye can see. A lot of farm equipment passed us on the road today, and a lot of the drivers, as well as a motorcyclist, encouraged us with shouts of, “Go, Irish!”

Unfortunately, my tri bike frame broke today – an unusual problem for bikes like this made from carbon fiber. We’re working with the bike shop back home to get a replacement. In the meantime, I have a spare bike, so the ride goes on.

York, NE to Holdrege, NE

June 6, 2012

GO IRISH!
Today was a perfect day to ride! It was the easiest day by far, complete with a tailwind instead of those headwinds and crosswinds I’ve been battling for some time. It’s really too bad my tri bike frame broke yesterday (I am still waiting for a solution with the bike store in town); it would have been a perfect day to ride that frame. We did some retrofitting on the road with the other frame. Those Zipp tires from SRAM that Jeff donated are something else! I can really zoom along.

Today felt like we started in the Midwest because we were still in the middle of a lot of corn fields near Holdrege. As we traveled to McCook, the landscape transformed into big rolling hills with beautiful wheat fields and lots and lots of cattle. I took a break from riding to play in the wheat fields for a bit. McCook, Nebraska is really a neat little town.

Today was also the first day of the Michael, Marcia, and Christa Parseghian Scientific Conference for Niemann-Pick Type C Research at Notre Dame. The conference kicked off with lunch in the Jordan Hall Galleria. More than 100 participants represent 31 institutions and five foundations at the conference. The gathering includes researchers, NPC families, and representatives of pharmaceutical companies from eight countries – the United States, Canada, Brazil, Germany, the Netherlands, Switzerland, Australia, and France. There are 17 NPC family members and three patients: Everett, an adorable 10-month-old; Tammy, whose diagnosis has been elusive, but who may have adult-onset NPC; and 12-year-old Lili, who came with her mom and dad from Germany.

I beamed in via Skype to welcome everybody and to thank our bike ride sponsor, the Notre Dame Federal Credit Union. The credit union has been a great partner. Both Diedre and Jon from NDFCU were there today, and Diedre told the conference participants about innovative ways the credit union is helping raise money for NPC. The conference opened with a keynote address by Marc Patterson, a professor of child and adolescent neurology at the Mayo Clinic and a recognized expert in the field of NPC. Dr. Patterson provided a comprehensive overview of the evolution of NPC research from the first identification of the disease in 1949 to the present day. He ended by suggesting the metaphor of a journey to describe the search for a cure, which is still unfinished. He also called for a greater degree of precision in engineering diagnostic methods and expanding efforts at education and awareness about NPC.

Following Dr. Patterson’s talk, there was a session on molecular and cellular biology, in which presenters discussed intracellular protein-protein interactions involved in cholesterol trafficking as well as the pros and cons of using induced pluripotent cells to build disease models as an alternative to animal models. The evening ended with dinner and open-format discussions for NPC families and for researchers.
June 8, 2012

Today was a more challenging ride - the crosswind was back, and it was blowing at 15 mph with gusts of 28 mph. It looks like we’ll have more of that tomorrow and it will be hotter, but the winds should ease off a bit. That will be nice.

I left very early this morning and the sunrise was spectacular. The sunrise is always one of my favorite parts of the day. The prairies and wheat fields were marvelous and looked beautiful blowing in the wind. As we crossed into Colorado, we probably could see 50 to 100 miles in all directions. The train off in the distance, probably a mile long, looked like a toy in the landscape under that big blue sky. We’ll see the Rockies tomorrow as we head toward Denver.

The ride was exhausting, but my energy gets restored when I think of the NPC kids and their families. I wish I could be at the NPC conference at Notre Dame this week, but it’s great to hear all the news from this wonderful event. Thursday night after dinner, the NPC patient advocates got together for an informal discussion. Representatives from Dana’s Angels Research Trust (DART), National Niemann-Pick Disease Foundation (NPPDF), Race for Adam, and Support for Accelerated Research (SOAR) discussed their fundraising efforts. Cindy Parseghian talked about the current research grant process at the Ara Parseghian Medical Research Foundation (APMRF). The parents also talked about their feeling of helplessness when insurance companies refuse to pay for treatments that have not yet received FDA approval, even though research has shown the treatments to be effective. These treatments are very expensive, often about $100,000, so the families are in a very difficult situation.

Friday’s scheduled was packed with talks from 8 a.m. to 6 p.m., and even the hour-long lunch break was largely taken up by stimulating discussions after the presentations. In the morning, researchers discussed their work on novel and existing biomarkers, compounds used for diagnosis and evaluation of potential treatments. Then came a very promising report on the progress of two Brazilian teenage girls, who have shown significant improvement after a two-year cyclodextrin regimen. A clinician from Germany presented on the psychological and psychiatric aspects of NPC, a previously untouched area in NPC research. On her way to South Bend, she stopped for several days in Texas to visit and interview a patient, and she showed the video of those conversations. In the afternoon, talks focused on two potential treatments that are being prepared for clinical studies in the United States: histone deacetylase inhibitors (HDACi) and cyclodextrin. One presenter discussed the process of repurposing a previously approved drug for NPC.

The highlight of the day was a patient’s perspective presentation, given by a wonderful family from Germany who came to the conference with their 12-year-old daughter, Lili. Lili’s parents took turns narrating their story: six agonizing years in search of a diagnosis as they watched their daughter’s decline. The couple had discovered through extensive Internet research that Lili’s symptoms resembled NPC, and a doctor finally confirmed the diagnosis. The story was so poignant and moving that the audience sat in several minutes of silence before they could continue with the session. We are very grateful to this family for their willingness to travel to South Bend all the way from Germany and to share their heartbreaking story with us.

Although I am not at the conference in person, I am making sure to get all the news from the sessions and the talks. I am so inspired by the children, the families, and the scientists so dedicated to raising our understanding and finding a cure.
Dear Greg,

We want to say thank you to you for your ride for hope and for gathering so many dedicated clinicians and researchers for the conference at Notre Dame. We were very happy to be part of this outstanding conference. Now we are strengthened again for our everyday life with NPC.

Thank you so much!

Go n-éirí an bóthar leat
Go raibh an ghaoth go brách ag do chúl
Go lonraí an ghrian go te ar d’aghaidh
Go dtite an bháisteach go mín ar do pháirceanna
Agus go mbuaлимid le chéile arís,
Go groinní Dítha i mbói A láimhe thú.

May the road rise to meet you
May the wind be always at your back
May the sun shine warm upon your face,
The rains fall soft upon your fields
And until we meet again
May God hold you in the hollow of His hand.

Sabine Fornfeist on June 8, 2012
June 9, 2012

The rising sun this morning was spectacular. The rays hit the van in a way that lit up the more than 300 gold signatures we’ve collected so far. That sun got hot as the day went on with the temperature reaching nearly 100 degrees in the strong wind. The landscape is vast – miles and miles to the horizon. Four antelope joined us for a few miles of the ride, running in the adjacent field parallel to the road. It was really cool to watch them slow down for a while, then accelerate to catch up with us. They are so fast! A train came by near the road, and the engineer played his version of the Notre Dame fight song for us with whistle toots – not exactly how it goes, but a really nice gesture. Little things like that really make a big difference to me out here.

Of course, the biggest thing that keeps me going out here is the goal of defeating NPC. It was great to hear about the successful conference that ended today. What a wonderful gathering that brings together the terrific team committed to this fight – the families, the researchers, the supporters, and most of all the precious children. Cindy Parseghian said it so well in her closing remarks – the children show us what we’re fighting for and why we’re all here. Thanks to everybody for getting together for the video cheer. The whole crowd came on the stage at Jordan Hall, which was really inspiring and came at just the right moment.

We pulled into Denver today and had a pleasant dinner with a few alumni, including Bob, the former president of the Notre Dame Club of Denver. Dinner was a nice chance to wind down after a hard week. We can already see the challenge ahead of us for Monday’s ride – up and over the Rocky Mountains. The Rockies will be quite a change in the territory. There are piles of snow here in Denver, and there’s sure to be more in the higher elevations. Fortunately, Outpost Sports is sending me a new tri bike via FedEx to replace the one that broke. I can’t wait to ride it on the other side of the mountains. I can go about 3 mph faster on the tri bike, so with a new one and my Zipp rims from SRAM, I will be in California in no time.

“Notre Dame is a place where we build community, and we all here are a community.”

– Cindy Parseghian
Today was our only day off from the ride so we could rest and prepare for what is in store for tomorrow. We will go up and over 12,000 feet.

We had a great alumni club event in Denver tonight at Little Man Ice Cream in the Highlands neighborhood. Everyone was treated to an ice cream and we had some raffles and auctions for autographed Ara footballs and Muffet basketballs, and even a Coach Parseghian bobblehead. Special thanks to Bob, Kevin, and Marcia from the club. It was a wonderful night. We had lots of little Domers in attendance, and several science students and science graduates showed up. Thank you, Denver, for your hospitality.
Well, I knew today was going to be a tough, tough day. During the first part of the day, Laura, a Notre Dame alumna and member of the Denver Club, rode with us for a few hours. It was a lot of fun talking about Notre Dame and, of course, football. Thank you for riding with us, Laura! After you turned around we hit a rough patch of road with loose stones for about six miles.

Today was all about climbing. First we climbed to about 9,000 feet and then descended into Estes Park, which is a beautiful town. On the way back up to the summit of 12,100, we saw snowplows still sitting out, lots of snow lying around, and some very challenging hills.

As I was riding up the mountain and telling myself what a terrific challenge this was, I could not help thinking about the much more difficult challenges NPC children and their families face – day after day, hour after hour, minute after minute. I am so honored to be able to ride for them and to raise money and awareness. These families and children inspire me. I am so honored to know so many of the families and children and to work with the Parseghians on this cause.
We left Granby at 6:00 this morning and the temperature was 36 degrees. I was wearing so many different layers that it was hard to ride. I am not fond of cold weather and 36 degrees on a bike feels really cold. Despite the low temperature and the high altitude, this was the task for today.

The ride to Craig was a long one – nearly 125 miles with a lot of climbing. The first formidable challenge was the climb over Rabbit Ears Pass reaching about 9,500 feet. The Rabbit Ears Pass is made up of two summits or passes. If you were at the bottom of the mountains and looked up, the two mountains look like a rabbit’s ears.

The climb up was challenging, but the descent was seven miles long with a 7% grade. I reached speeds of about 45 mph without pedaling! I started to scare myself, so I held on dearly to my brakes. The decent was certainly an easy, quick way to cover ground. I noticed something funny on the ride today: in Iowa and Nebraska, every new city or town lists its population on the sign, but in Colorado, every new town’s welcome sign lists its elevation.

After our descent, we rode through Steamboat Springs. It was beautiful – just a quaint little city set up for biking and hiking in the summer and skiing in the winter.

The landscape changed a lot today – from barren desert-like, to green with lots of evergreens in the mountains, to bare rocks, and back to desert-like. Overall, it was a pretty riding day except for the wind that whipped up to more than 20 mph for the last 30 miles. Everyone told me that most people who undertake a ride across the country go from west to east in order to have the wind at their back – with the winds that we’ve had thus far, I can certainly see the benefit in going the other direction.

I just keep thinking about those NPC kids and families and the Road to Discovery for the cure – that keeps me going!

June 12, 2012

More than half of the ride would have been with the wind at my back.

Well, at the end of this windy road, we’ll be at Pebble Beach with Notre Dame alumni and friends for our golf fundraiser for the NPC research. The wind has definitely added a big extra challenge, but it’s all worth it. I just keep thinking about those NPC kids and families and the Road to Discovery for the cure – that keeps me going!
Today was a wonderful ride, marked by contrast. We started in Craig, where there is still a lot of green, and ended in Rangeley, which is a beautiful desert. I just love the desert landscape. We saw some pronghorns that live out here. We could see them off in the distance moving around, but they never got too close to us.

A reporter met us on the outskirts of town to hear our story. The last three days in Colorado resulted in 20,000 feet in cumulative climbing, 350-plus road miles, and more than 50-degree temperature swings from morning to afternoon. It has been a wild ride all along, but especially in Colorado. It’s tough for somebody who lives in Indiana to acclimate to this altitude. Only today have I started getting used to it. Living and training in the South Bend area, there’s only so much you can do – training at altitude and uphill are two things that you cannot simulate. But the trainers at Knollwood did a great job getting me ready for this journey. With fewer than 1,000 miles to go and single digit days left to ride, I will be excited to see everyone in Pebble Beach.

Today as I rode through the long, vast stretches of desert, where at certain vantage points you can see the road going on for tens of miles, I really felt like I was on the Road to Discovery. In his keynote address at the NPC conference, Marc Patterson suggested that we think of our effort as a journey. We have come a long, long way, especially in recent years, and research is making the road ahead ever clearer. I can identify with that image. We face our headwinds, our rocky roads, our steep uphill climbs, and sometimes we get to see how much progress we have made and gain confidence that we are going to make it to the goal. Those NPC children and families are counting on us to find a cure. We are committed together to reaching that finish line.
Those NPC children and families are counting on us to find a cure. We are committed together to reaching that finish line.”

—Dean Greg Crawford
This day started out great – warm and no wind – and just kept getting better. The desert scenery was absolutely gorgeous, both in Colorado and in Utah. We saw more pronghorns, and lots of bunnies ran across the road. This is dinosaur country, too – there’s even a Town of Dinosaur just on the Colorado side of the state line, with big dinosaurs in town.

When we got to Vernal, Utah, still in dinosaur country, we had a nice 10-mile downhill. We arrived at the ranch where we’re staying tonight, and it’s really cool – desert, lakes, totem poles, anything you can think of from the Wild West is here. Overall, this was a wonderful, nearly perfect day!

June 14, 2012
“Today as I rode through the long, vast stretches of desert ... it really felt like the Road to Discovery.” —Dean Greg Crawford
Today was an absolutely spectacular ride through the mountains from Altamont to Park City. We stayed on a ranch last night, and it was wonderful. The house was rustic, and Ann cooked us a great meal. The sunrise this morning was unbelievable. We reached about 9,500 feet on our climb through the Wasatch National Forest. As we descended into Park City, we saw beautiful mountains and lakes everywhere we looked. Wendy from the local television station met up with us to do a story, and while she was filming on the street, a Notre Dame graduate who lives and works in Park City walked up to meet us.

One highlight of the day was crossing paths with the veterans riding their bikes across the county in the other direction—we passed each other. Known as the Sea to Shining Sea ride (www.s2ssbikeride.org), they were an amazing inspiration to me. Thank you, veterans and military personnel, for all you do for our country and the sacrifices you make for us.

Park City is an ideal town—looks like it is out of an old-fashioned movie, with not a piece of litter on the ground or a blade of grass out of place. It is perfect. We had a little event at the Wasatch Brewery right in Park City, with local alumni from Salt Lake City and Park City and a few students who are in town doing their summer service-learning project. What a wonderful place and community.
Today was a day full of new sights and I felt like a tourist rather than a bicyclist passing through. First we stopped at the Park City Olympic Center, really a neat place where they awarded many of the medals during the 2002 Winter Olympics. We left Park City early on a beautiful hill climb outside of town, and we must have passed several hundred other bicyclists. It is a bicycle heaven out here in Utah.

We descended into Salt Lake City – I mean a really steep descent – and the first stop was “This is the Place” Heritage Park. The park marks the location during the 1847 migration of the Church of Jesus Christ of Latter-Day Saints where their leader, Brigham Young, announced that they had arrived at the spot that fulfilled his vision to “make the desert blossom like a rose.” He was riding in the back of a wagon because he was ill with Rocky Mountain spotted fever, but when the Mormon pioneers reached the crest of a small hill, he looked down into the valley and gave the word: “It is enough. This is the right place. Drive on.” Heritage Park is absolutely stunning for its beauty and its history.

After the park, we made our way through the beautiful University of Utah campus and visited its version of Innovation Park, which is very large and integrated with many companies and centers associated with the medical school. As we came through the campus, we ran across a celebration of Fort Douglas, the military garrison that was established in 1862 and mostly turned over to the university after it closed in 1991. Part of the old fort, including Fort Douglas Military Museum, is used by the Army Reserve. The historical celebration included re-enactors portraying the various stages of the fort’s history from the Civil War to the modern military.

Then it was on to the Salt Lake Temple, the Mormons’ best-known temple and the heart of Temple Square in the city. The architecture was spectacular. I also visited the Mormon Tabernacle and heard a bell choir playing. The acoustics are unbelievable – they say you can hear a pin drop from anywhere in the tabernacle. We saw many tour groups enjoying both the temple and the tabernacle.

After Salt Lake, we passed the airport and onward to West Wendover, Nevada. We stopped at the Bonneville Salt Flats close to the Nevada border. The famous densely packed salt pan is a remnant of ancient Lake Bonneville, which was as big as Lake Michigan and included the Great Salt Lake and many smaller salt flats in the area. The flat land is famous for speed records, including the bicycle speed record of 167 mph by a Dutchman who was pedaling behind a race car for favorable aerodynamics. I didn’t set any speed records, but I sure had fun pedaling around. People were out sunning and doing yoga, and some were racing their cars and spinning doughnuts on the salt flat. I was completely covered with salt, and so was my bike. Bonneville probably ranks as the most unusual place I have ever been.

Tonight we are staying at a hotel in Wendover, Utah, but the state line is on the street right outside. Once you cross it into West Wendover, Nevada, there are casinos everywhere. It was quite a day, filled with lots of sightseeing and learning about the remarkable history of Utah.
Today’s ride was long – about 120 miles – which would have been challenging enough, but on top of it we had headwinds that averaged 20 mph with gusts exceeding 30 mph. That’s hard for biking.

On the positive side, we got to set our watches back an hour. We’re now in the Pacific Time Zone, which makes it feel like we’re all that much closer to Pebble Beach. When we were riding in to Ely, which is mostly a casino town, we could see a large forest fire in the mountains to our left.

Tomorrow’s forecast looks like more of the same, hot and windy. Today was pretty uneventful, but that’s OK – yesterday was such a packed set of experiences that it felt like several days’ worth.
We expected to face strong headwinds today, and today was the worst yet with gusts of more than 35 mph. About 20 miles before we reached Fallon, we saw Sand Mountain, which is another remarkable geographic feature like the Bonneville Salt Flats. Sand Mountain is also related to a prehistoric lake, but it’s a singing sand dune, meaning it makes a music-like sound when the wind blows over it. The dune is two miles long and 600 feet high – quite an impressive sight.

Andre, an alumnus, organized a get-together tonight that included several alumni and a current science student after we arrived in Fallon. We had a great time.
Today was a very, very special day for me. During the first part of the day, I biked 65 miles from Fallon to Carson City, NV, where I had the opportunity to have a very inspirational meeting. I met two special little girls, Cassidy and Addison Hempel. Cassi and Addi are 8-year-old twins with Niemann-Pick Type C disease. Their parents, Chris and Hugh, as well as their grandparents, brought the girls to meet me.

I rode into Carson City looking for the twins near the state house. When I arrived, I saw two little girls with balloons waiting for me in their custom-made bicycles. Not only were they waiting for me on their bikes, but they were also holding up a Notre Dame banner! I was so touched by the welcome.

These twins were diagnosed with NPC in 2007. I also want to thank the press and media who visited us today along the ride. Raising awareness for NPC is one of our primary goals, and I appreciate your interest in the NPC families and the ride.

After we left Carson City, we biked into California at Lake Tahoe. Karyn and Charles, parents of one of our recent graduates, Brooke, had dinner with us in town. It was such a wonderful dinner and evening.

“When I arrived, I saw two little girls with balloons waiting for me”

Today was also a fun day on the road because I was able to ride my tri bike. You may remember that my other tri frame broke earlier on the ride, and I was without one for part of the trip. Outpost was kind enough to send me a replacement on the road. Thank you, Outpost, for taking care of this for me. I really appreciate it.

“Addi and Cassi add their handprints to the van.”

Thank you again to everyone who helped make this a wonderful day that I will never forget.
The air was chilly this morning when we left Lake Tahoe, but the scenery was just spectacular. It was sunny and beautiful as we crossed up and over Echo Summit, which is over 7,000 feet from sea level. The views were absolutely breathtaking. Today, I rode about 110 miles ride to Elk Grove, Calif., right outside of Sacramento. Scott, a Notre Dame Law alumnus, rode with me for the first 60 miles of today’s journey. We had a lot of fun and made a big cheer right before we crossed the summit.

After Scott’s wife picked him up, the ride became less enjoyable. I hit a 7-mile dirt road that really rough and full of big holes. Some spots were so rugged I had to carry my bike down the road. The good news was that the road wound through some of the most pleasant rolling hill landscapes with rocks and ranches that I have ever seen. Just as we came out of that 7-mile stretch, we discovered that the road was closed, and a detour added more miles to today’s ride. I am at the point where I will take any shortcut whatsoever to knock off a mile or two.

Finally, after the rough road and extra miles, I rolled into Elk Grove, which is a wonderful suburb of Sacramento. Despite some of the rough parts of the ride, it was a great day overall and we had no wind! The local media came today and interviewed me and filmed some video of the van. The signatures on the van are piling up and all of the reporters and newscasters just love the concept of signing it.

This evening we had a gathering with the Notre Dame Club of Sacramento. Eva, the club president, organized a great event at Romano’s Macaroni Grill. There was a good turnout with graduates, incoming freshmen, and one student hoping to attend Notre Dame after high school. Thank you, Sacramento club, for your hospitality!
Today was a tough 92-mile day with strong headwinds. Yesterday, the temperature reached 100 degrees by the end of the ride, but today, the temperature made it to 60 degrees. Yesterday, dirt roads, which are tough on a road bike, were part of the route. Today, we passed our hotel and rode 17 extra miles because of a GPS glitch. Advice to those preparing routes for bike trips: do not use roads that pass through Windy Cove State Park or through miles and miles of wind farms. There is a reason the word "wind" is in those names.

Well, enough about the wind. Tomorrow is my last day, and I am looking forward to it. It has been an interesting ride this year and a real pleasure working with our wonderful sponsor, the Notre Dame Federal Credit Union. They really share my passion and the College’s mission to do great things in the world, like finding a solution to NPC. They have been such a great partner and I can’t thank them enough.

After we got to the hotel in Livermore, Nancy, a recent physics graduate, stopped by to sign the van. This evening we had an event in San Francisco at an Irish pub. Bailey, the club president, did a great job at organizing the gathering. How is this for luck – we drove in to San Francisco and got a spot for the van right in front of the pub! Thank you, Notre Dame Club of San Francisco, for your hospitality. It really enjoyed the evening and it was a lot of fun being with you.

It has been a long haul, but I am delighted to have the opportunity to ride for the children with Niemann-Pick Type C and their families, to raise funds and awareness for NPC, and to let the country know about the our science research and our passion to find a cure this disease.

June 21, 2012
“This journey to find a cure for NPC is a great example of why the Fighting Irish fight. We fight for the life, dignity, and well-being of every person, and I am honored that the Road to Discovery is part of that purpose.”

–Dean Greg Crawford
Day Thirty Three

June 22, 2012

The final day of the ride was uneventful, but beautiful. There were two very big climbs to get over to San Jose from Livermore, then one more climb to get to Monterey. The ride was so pretty that it was hard to think about how tired my legs have been. Along the way today we saw deer, wild turkeys, and other wildlife. I could not have asked for better weather or more beautiful nature.

We rolled into Monterey at around 2:30 p.m., and I had an hour or so to spend at the beach reflecting on the ride before the last 10-mile leg into Pebble. I thought about all of the NPC families and kids who face tremendous challenges every day and persevere through them. I thought a lot about Cindy and Mike Parseghian, and their amazing efforts to fund scientific research to find the cure. They have been such wonderful partners to us all at Notre Dame. I thought about Michael, Marcia, and Christa, the Parseghian children. I thought a lot about all of the families and kids I met last year during the ride with Renate, my wife, and all those I have met at the conferences the past few years. I thought about seeing those precious twins, Addi and Cassi, waiting for me on their bikes a few days ago at the state house in Carson City. It has been a real honor to ride for all of these children and families, and I am so happy they have embraced the ride and our scientific efforts at Notre Dame. We are on this journey together, and we will keep supporting each other until we have crossed that finish line. Thank you so much for the inspiration you have been to me on this journey across the country.

After the tire dip, we had a wonderful dinner with an open pit fire. The company was fantastic. I had the opportunity to thank Ann and Dan Monahan for their recent endowment to hire a faculty member in rare and neglected diseases. This gift will help us recruit the best faculty talent to Notre Dame. Thank you so much, Ann and Dan, for your amazing generosity and love for the university.

Bill Perocchi, the CEO of Pebble Beach who has sent his children to Notre Dame, told us a little bit about the course and the history of Pebble Beach. He pointed out that visiting the resort is on many people’s bucket lists, just like seeing a Notre Dame football game. After Bill spoke, I invited Tom Gryp, president of Notre Dame Federal Credit Union, to be recognized. Thank you so much, Notre Dame Federal Credit Union, for your support and sponsorship of the ride. I would also like to thank Jon at NDFCU for attending the alumni events all around the country and Deidre for all of her effort and support. It has been a great partnership, and we look forward to working with NDFCU in the future.

Well, the ride is officially done for this year! Thank you all for following my blog, thank you for your support, and thank you for helping Notre Dame and the Ara Parseghian Medical Research Foundation move forward to a cure on the Road to Discovery.

“It has been a real honor to ride for all of these children and families, and I am so happy they have embraced the ride and our scientific efforts at Notre Dame. We are on this journey together, and we will keep supporting each other until we have crossed that finish line. Thank you so much for the inspiration you have been to me on this journey across the country.”
“Cindy and Mike went down to the water with me where I dipped my front tire into the Pacific, completing the tradition that I started by dipping the rear tire into the Atlantic, way back in Boston with Cindy and Mike’s son Ara. What a great finish.”

“Cindy and Mike were able to also dunk the bike that their son Ara rode on the first leg. What a great ending to this year’s ride.”
The Parseghian Golf Classic was a fantastic event. Held at Pebble Beach for the first time, 40 golfers, plus spouses and guests, enjoyed the spectacular beauty of Pebble Beach, 17-Mile Drive, and the picturesque surroundings - all for a great cause. On Friday night, we started off with the tire dip.

As I pulled in on my bike to wrap up the 3,300-mile ride, it was so nice to see everyone waiting for me by the water. Cindy and Mike were able to also dunk the bike that their son Ara rode on the first leg. What a great ending to this year's ride.

That evening we had an outdoor gathering with an exceptional dinner. We had a chance to thank many people including Ann and Dan Monahan for their endowment that will support a line of faculty members in perpetuity in the area of rare disease. We also thanked Bill Perrochi, CEO at Pebble Beach, and his wife for providing us with such a wonderful venue for the fundraiser. Mr. and Mrs. Perrochi are also Notre Dame parents. We also said a big thank-you to Tom Gryp, president of Notre Dame Federal Credit Union, for supporting the ride, and Jon Crawford from NDFCU for meeting with Notre Dame alumni around the country as I rode through the various cities and towns. It was a fantastic evening.

After a great oatmeal breakfast on Saturday, we were off to Spanish Bay to play 18 holes. The views were just amazing and the course and weather were perfect. It is a place of splendid beauty. The teams were out early to enjoy the beauty of the course and the challenges that awaited them on the drives and greens. I did not golf this weekend as I was too stiff and sore, so I rode around with the photographer and had a great time watching everyone else play.

Sunday was a round of golf on Pebble Beach (the famous Pebble Beach) with some of the most fantastic scenery I have ever witnessed. It is hard to convey the beauty of this place — you just have to see it to believe it. Even the individual holes on the course are famous, such as the Par 3 on No. 7, the most photographed golf hole in the world, and of course No. 17, where a brand-new Mercedes Benz sat waiting for someone to win it with a hole-in-one. No one walked away with the big prize, but it sure was fun to watch everyone try. Jon Crawford was waiting at the end to congratulate everyone and give them a Notre Dame Federal Credit Union golf towel.

The night was a lot of fun at the Beach Club at Pebble, where we announced the awards for the weekend. Cindy's team was the first place. Of course, she had Jean and the two Notre Dame golfing coaches, Kyle and Susan, on her team. Mike's team came in second. A big thank-you to Cris and Nicolle for all of the organization and hard work they put in for this event. At dinner, Renate and I presented Cindy and Mike with a Notre Dame Science Quilt and a framed piece of the van wrap from last year's ride signed by country music artist Amy Grant.

Cindy gave us all a thank-you as well as some inspirational words on searching for the cure. The dinner was great and the night ended with Gary Mule Deer, a comedian who was just hilarious. We laughed and laughed for about 45 minutes. What a great guy!

Well, that just about wraps it up. Thanks to all of you who have followed the blog and to all of those who have contributed to the Road to Discovery. Thank you for sharing our passion for finding a cure for NPC and for being part of our mission at the College of Science.