

# FPN News

the FOUNDATION for  
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FALL 2010

## A MESSAGE FROM THE EXECUTIVE DIRECTOR



Every choice  
we make;  
every action we  
take—matters.

Every day we are reminded that the work of the Foundation is vitally important. From the questions we receive on our Facebook page to the personal stories we hear from patients, we know that their challenges are real and what we do matters. The research we are funding today will foster the innovations that will become much needed treatments, and eventually a cure, tomorrow.

The generosity of people like you enables us to continue supporting the ground-breaking research that will provide new and effective PN therapies. We need you, your family and friends to get involved with FPN and the PN community to make a personal impact on our journey to reversing the irreversible. We are grateful for all those who supported the Foundation during 2009 and those who have remembered the Foundation in honor or memory of loved ones.

As we continue to search for answers, FPN will be dedicated to working with patients, providing resources so they can define themselves not by their disease but by positive attitudes and actions. You will hear more about this in the coming months.

With this Spring issue, we highlight why research matters, share inspirational stories and the activities of the Foundation—all with the hope of helping you live well with PN.

Warm Regards,

Pam Shlemon

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## Our Pledge

You have probably heard about the challenge Bill Gates and Warren Buffett made to their fellow billionaires—give at least one-half of your fortune to charity! The challenge is called **'The Giving Pledge'** and there are now 40 billionaires who have agreed to donate at least half of their fortunes to philanthropic causes.

So, how will they be giving their fortunes away? There are as many ways to give as there are people! Bill and Melinda Gates have committed the largest portion of their Foundation resources to bringing innovations in health, development and learning to the global community. Warren Buffett will give 99% of his wealth for the health and well being of others through various means. Paul Allen, co-founder of Microsoft, focuses on issues in the Pacific Northwest through his Foundation but his estate will also be ear-marked to fund non-profit scientific research. Roger Sant, founder of the global power company AES, and his wife Vicki, want to fulfill their mission of creating a world

'where nature can flourish and people can thrive.' Jim and Virginia Stowers have already created the Stowers Institute for Medical Research; Jim was the founder of American Century Investments. The list goes on and touches every aspect of our society—and world.

*Forty billionaires have  
agreed to donate at least  
half of their fortunes.*

Why do people take up the challenge to give away billions of dollars? The answers to that are almost as varied as the causes they support. Sanford and Joan Weill (banker and financier), "want to leave the world a little better than we found it." Ted Turner (founder of CNN) knows that his dollars, "have improved lives, fought disease, educated children and inspired change." Pierre and Pam Omidyar (founder of eBay), say, "it's about discovering the most efficient and effective use of our resources and leaving a legacy of hope for those to come."

(CONTINUED ON PAGE 3)

## BEN—HIS SUMMER IN THE LAB

Medical research has led to the development of treatments and cures for disorders that only a century ago were considered incurable. From an outside perspective, medicine seems to have an almost magical quality. From the inside, however, research is an in-depth and time consuming process and breakthroughs can take decades to come to fruition. Thanks to an internship at the Johns Hopkins School of Medicine, one undergraduate student has been able to experience research from all angles.

Ben Cocanougher, now a senior at Centre College in Kentucky, spent his first summer there working at the Center for Courageous Kids, a camp for children with life-threatening and life-altering illnesses. Cocanougher worked firsthand with children and families affected by multiple types of neuromuscular disorders. This experience allowed him to connect with patients and families who struggle to make sense of something they don't understand and can't control. When asked about the experience, Cocanougher stated that he "met many families that have expressed frustration wondering, if you throw enough money into research, why isn't there a cure?" Having experienced both the frustrations of families and the day-to-day work of researchers, Cocanougher has gained a greater perspective on the process and progress of science.

This past summer, Ben was selected as a summer research intern at Johns Hopkins School of Medicine, a renowned research institution that has been directly involved in many of the breakthroughs of modern medicine. Cocanougher chose to work in the Department of Neurology due to his previous experience with children affected

(CONTINUED ON PAGE 6)

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# RESEARCH

## RESEARCH NEWS

Often it seems like there's not much happening in the world of PN. Patients keep wondering if anyone is doing anything while they keep waiting for new treatments. Here are four major developments that bear watching, two of them out of the University of Kansas:

### DRUG HOLDS PROMISE TO HALT DEBILITATING CONDITION OF DIABETES

Researchers at the University of Kansas have published an article showing that they have developed a drug that has the potential to stop, and even reverse, diabetic peripheral neuropathy (DPN) in mice. DPN leads to death of the nerves in the extremities of individuals with diabetes.

Rick Dobrowsky, professor of pharmacology and toxicology at KU and one of the authors, explains, "DPN often leads to loss of feeling in the hands and feet, which can make diabetics susceptible to wounds and infections and often leads to amputations of toes and feet." DPN is the second leading cause of amputations, after injuries.

With nearly 24 million diabetics in the United States, almost 60 percent of them suffer from DPN at some point. The researchers hope their drug can eventually be used to help treat the condition in humans. Their research shows that the new drug could be administered orally as infrequently as once a week and still be effective. "It is a promising treatment."

The KU article was published in the American Society of Neurochemistry journal, ASN Neuro.

Source: Science Daily

### RESEARCHERS SUGGEST A COMMON CHAPERONE PROTEIN CAN REVERSE DIABETIC PERIPHERAL NEUROPATHY

Michael J Urban and colleagues at the University of Kansas suggest that the use of a heat shock protein, Hsp90, could be used to reverse the loss of function in the nerves of mice with diabetes. Caused by increased blood glucose levels that lead to a breakdown of key proteins, DPN is a difficult condition to cure with treatments limited to heavy glucose control and pain management.

This study, in conjunction with the previous results of the research at the University of Kansas, has led to the reversal of neuronal degeneration in mice with DPN. The findings of this study have been published in ASN Neuro.

Source: The Medical News



### 13TH WORLD CONGRESS ON PAIN

The results of a new study by DARA BioSciences were presented at the 13th World Congress on Pain in Montreal, Canada. The study was designed to evaluate the safety and efficacy of a new drug to treat neuropathic pain in patients with cancer.

The prevalence of Chemotherapy-induced Peripheral Neuropathy (CIPN) is reported to be as high as 38% in patients who receive multi-agent chemotherapy. There is currently no approved treatment for CIPN. So, exploratory analyses of study patients provided clinically meaningful results regarding this new treatment.

The new drug was effective in reducing pain in patients with CIPN; and a dose-response relationship was established with higher doses resulting in greater reductions in pain. The new drug was well tolerated with adverse reactions limited to nausea and vomiting.

DARA BioSciences and the National Cancer Institute entered into a clinical trial collaboration to further study the new drug earlier this year.

Source: The Medical News

## news Briefs

### Does marijuana really relieve pain?

*The use of marijuana for a few carefully selected medical conditions has generated heated discussion. Absent from the debate so far, is scientific evidence to establish whether marijuana really works to relieve chronic pain. And, if it does, whether it does so in a manner that is distinct from simply providing the well-known high that has made it a popular recreational but illicit drug.*

*Researchers at McGill University, Montreal, Canada, conducted a study that shows that the highest level of a 'pretend cannabis' reduced levels of pain by a modest amount. In addition, the subjects' ability to fall asleep was improved and they reported a more restful night.*

Source: Montreal Gazette



### What You Can't Feel Can Hurt You

*Dr. Andrew Boulton of the Manchester Diabetes Center, Manchester, England, has published an article stating that the lifetime incidence of foot ulceration in people with diabetes has been estimated to be as high as 25%. However, virtually no time is spent on teaching how to manage patients who have no symptoms because they have lost the ability to feel pain; patients with peripheral neuropathy. Regular screening for peripheral neuropathy is vital in all patients with diabetes. Those found to have any risk factors for foot ulceration require special education and more frequent review, particularly by podiatric physicians. His key message is that neuropathic symptoms correlate poorly with sensory loss and that their absence must never be equated with the lack of risk of foot ulceration.*

Source: Journal of the American Podiatric Medical Association



## OUR PLEDGE CONTINUED

Of course, most of us aren't billionaires or even millionaires. And, with today's economy pinching us in ways we never thought possible, it's even tougher to imagine what it must be like to be wealthy. We like to think that if we were we'd be willing to give our money away, too. But, the reality is that you don't have to be a billionaire, or millionaire, to do your part. As the Omidyars know, it's about each of us finding a cause we believe in and making a commitment to making a difference. Every donation—large or small—counts!

Peripheral Neuropathy (PN) affects 20 million Americans. So many of them contact us—wanting a new treatment that might help, to talk about how they are suffering, wanting to know if anything is being done. There is research that is taking place and new treatments are being tested but, if those of you who are suffering, or know someone who is suffering, commit to helping the Foundation reach our goals, we will begin to see more progress. We may not see a cure in our lifetime, but you will know that you have made a difference.

What does the Foundation do with the money that you give? There are many ways your donation will be used to further our mission:

- ▶ **FPN-DR** – a multi-site data registry of patients with PN that can be used for studies and research to find new treatments
- ▶ **YOUNG INVESTIGATOR AWARDS** – grants to bring new, young research scientists into the field of PN
- ▶ **FPN RESEARCH SYMPOSIUMS** – conferences to bring leading researchers, scientists and physicians together to discuss the current state of PN and collaborate on new directions for research
- ▶ **EDUCATIONAL PROGRAMS** – patient, caregiver, and healthcare provider seminars to build awareness of PN, its causes and symptoms, and teach coping skills for every day living

Each person participating in **The Giving Pledge** does so out of a sense of wanting to give back, to leave behind something bigger than themselves and what they have accomplished. At the Foundation, we are committed to achieving the most we can with what we are given. We hope you will make a pledge to join us in our work. We call it our **'Make a Difference Today'** pledge. It's our pledge to you.

# PNRR

## Peripheral Neuropathy Research Registry

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## CLINICAL TRIALS

### A Phase I/II Open Label, dose Escalation Study to Assess the Safety and Tolerability of VM202 in Patients with Diabetic Peripheral Neuropathy Northwestern University

Chicago, IL

High blood sugar, reduced blood flow in the limbs, and changes in the blood vessels are thought to result in damage to the nerves in the affected areas. Stimulating the growth of new blood vessels may reduce pain due to diabetic peripheral neuropathy (DPN).

Northwestern University, in partnership with the Northwestern Medical Faculty Foundation and Viomed Co. Ltd., has started a clinical

research study where the HGF gene will be injected into research subjects to evaluate if it changes their pain related to diabetic neuropathy.

It is hoped that the study drug injected into the calf muscle will reduce pain related to diabetic neuropathy. This study is intended to help determine: the safety and tolerability of three different doses of study drug, and if there are any effects of the study drug on symptoms of painful diabetic neuropathy.

Up to 14 subjects will take part in this study. If you are in the Chicago area and are interested in participating, please review the requirements

of the study on our website. If you believe you are eligible, you may contact Northwestern study coordinator Emily Kunka at 312-503-0160 or nwu-eck116@northwestern.edu.

### Glutathione in Preventing Peripheral Neuropathy Caused by Paclitaxel and Carboplatin in Patients With Ovarian Cancer, Fallopian Tube Cancer, and/or Primary Peritoneal Cancer

North Central Cancer Group

Multiple states/locations

You can read more about these clinical trials at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

# LIVING *well*

## TAI CHI

Dr. Li Li, Professor of Kinesiology at Louisiana State University, believes tai chi is a novel way to fight peripheral neuropathy. “Tai Chi, the eastern art of strength and meditation may be poised to become an affordable and powerful treatment option for people battling the debilitating effects of PN.” Since 2004 Li has been studying the effects of tai chi and the test results prove that tai chi is more than just a mind game—it really works!

Approximately 30% of people aged 60 and over will fall in any given 12-month period. In Sydney, Australia, a 16-week study was conducted to see if tai chi would reduce falls and improve balance in this age group. Results showed that falls were less frequent in the tai chi group than in the control group. And, there were statistically significant differences in changes in balance favoring the tai chi group on 5 out of 6 balance tests.

At LSU, Dr. Li continues to focus his attention on peripheral neuropathy. “This is a group of people who desperately need help,” Dr. Li says. Patient stories reflect a significant decrease in falls and increased confidence walking and standing. More traditional methods of exercise have also been studied but so far tai chi is the undisputed winner.

Source: The Medical News; Journal of the Neuropathy Trust; MedScape

**Disclaimer: Please remember to check with your doctor before you begin any exercise program. Also, make sure you let your instructor know that you have peripheral neuropathy.**



## Benefits of Tai Chi

REDUCE ANXIETY AND DEPRESSION

IMPROVE BALANCE, FLEXIBILITY AND MUSCLE STRENGTH

REDUCE FALLS

IMPROVE SLEEP QUALITY

INCREASE ENERGY, ENDURANCE AND AGILITY

IMPROVE OVERALL FEELINGS OF WELL-BEING

Source: Mayo Clinic

# Considering Acupuncture?

Acupuncture has long provided relief for pain, discomfort, and resulting anxiety.

The HanLing Acupuncture Healing Center in Tucson believes that using various forms of acupuncture in conjunction with other modalities, like light therapy, will reduce pain and restore sensation even for PN patients. They have found that multiple approaches help PN patients receive longer lasting effects of reducing pain and improving sensation throughout the hands and feet.

Additionally, a clinical study was done at the Heidelberg School of Chinese Medicine that would bear out their beliefs. Their pilot study evaluated the effect of acupuncture on PN as measured by

changes in nerve conduction and assessment of symptoms. Over the course of one year, 192 PN patients were evaluated with forty seven patients meeting the study criteria for PN of unknown causes. Twenty-one patients received acupuncture treatment according to classical Chinese Medicine. Twenty-six patients received medical care but no acupuncture for their PN. Of the acupuncture group, 16 patients (76%) improved as measured by nerve conduction studies; 3 patients showed no change and 2 experienced an aggravation. Only 4 patients in the control group (15%) improved during the study; 7 patients experienced no change and 15 an aggravation.

SOURCES: HANLING ACUPUNCTURE HEALING CENTER; PUBMED; CLINICALTRIALS.GOV

If you have Chemo-induced PN and are interested in the effects of acupuncture, M.D. Anderson Cancer Center in Houston is recruiting patients for a clinical study. Go to [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov) for details (NCT00891618)

Disclaimer: Please remember to check with your doctor before beginning any new treatment regimen.

► **TIPS FROM PATIENTS** Often we find that people living with PN have the best tips for improving the quality of each day....they know what works for them! So, from patients and our facebook fans, we've collected a few of the tips that we hope will bring you additional relief. Remember this is not a one-size fits all approach – you may have to try different options until you find one that works for you!

► **Having trouble sleeping?**  
–Try “placing a pillow between your legs/ calves.”  
[www.contourliving.com](http://www.contourliving.com) OR use your own

► **What kind of shoes work best?**  
–Try SAS – “expensive but super comfortable” - or Mephisto  
[www.sasshoes.com](http://www.sasshoes.com) or [www.mephistoshoes.com](http://www.mephistoshoes.com)

► **What to do in cold weather?**  
–Try Acorn padded slippers – “warm and very padded on the bottom. I live in them!”  
[www.acorn.com](http://www.acorn.com)

**And, the best advice—“be your own advocate and never give up!”**

# PROFILE DONOR SPOTLIGHT

## An Investment in Better Health—For All of Us!

Richard Easley, FPN Board of Directors

I've had peripheral neuropathy for about 10 years though I wasn't officially diagnosed with idiopathic neuropathy until 7 years ago. My neurologist gave me Neurontin, told me there's no cure and "have a nice life". Does that sound familiar? Too many of us have heard it.

I settled for taking the medication, eating better, doing low impact exercise every day (Tai Chi works for me), and waiting for a cure. Unfortunately, since that time, not much has changed in effective treatments and we don't seem to be any closer to a cure.

Today, I'm pretty sure the cure isn't coming during my lifetime. Our disease, though affecting 20,000,000 Americans with varying severity, is not really a killer. And, probably because it isn't life-threatening, it doesn't get the attention or funding that other diseases do that can affect a smaller portion of the population.

When I finally realized I couldn't just wait for others to fund better treatments, and perhaps a cure, I searched for an organization to which I would give money. I picked this Foundation for several reasons:

- Jack Miller, the founder, has PN.
- The Foundation's primary focus is research to find new and effective treatments, and eventually a cure.

■ **The Foundation is funding a patient database that will be used collaboratively by those doing the research it funds.**

■ **Last, but certainly not least, the Foundation is efficiently run by experienced professionals.**

So, simply, what I'm saying is this: Without money, research doesn't happen and PN just isn't getting the funding that you'd expect—or hope—given the number of people with the disease.

If those of us that have PN, or have a relative or friend with PN, don't step up to help fund the research, there won't be new treatments or a cure.

I am asking you to join us by giving what you can, plus a little more, to fund research for the treatment, and a cure, for PN. Your donation is an investment in better health for all of us.

*Mr. Easley's story is all too familiar but he knows that together we can make a difference. If you are interested in contacting him, please send him an email at [reasley1@comcast.net](mailto:reasley1@comcast.net). If you are interested in making a donation, please visit our website: [www.foundationforpn.org](http://www.foundationforpn.org) or give us a call.*

## ASK THE EXPERTS...

QUESTIONS SUBMITTED BY OUR FACEBOOK FANS; ANSWERS PROVIDED BY DR. SENDA AJROUD-DRISS, NORTHWESTERN MEDICAL FACULTY FOUNDATION AND DR. DAVID SIMPSON, MOUNT SINAI MEDICAL CENTER

**Q** "How can drugs used for anxiety and depression (e.g., Cymbalta, Lyrica) be effective in the treatment of PN?"

**A** An imbalance in the levels of the chemicals in the brain can cause depression and affect the brain's perception of pain. And, the biological mechanisms and anatomic pathways underlying neuropathic pain, depression and neuropathic pain are closely linked. Patients with neuropathic pain commonly suffer from anxiety and depression. Both Lyrica and Cymbalta change the levels of naturally occurring chemicals in the brain. By changing the levels of these substances in the brain, Cymbalta and Lyrica help alleviate the symptoms of depression, anxiety and neuropathic pain.

**Q** "Can lethargy be connected to PN?"

**A** Patients with neuropathic pain commonly suffer from sleep disorders. Pain, tingling and numbness are often worse at night and may interfere with sleep causing sleep deprivation. Furthermore sleep deprivation may heighten the intensity of neuropathic pain. These sleep deprived patients can become lethargic during the day. Also, medications used to treat the symptoms of painful neuropathy can at times cause fatigue and sleepiness during the day as a side effect.

**Q** "How long should it take for patients to feel some benefit from prescribed drugs?"

**A** Usually medications used for neuropathic pain are effective once they reach a steady level in your body but there is wide variability on the timing of response of relief of neuropathic pain with agents such as antidepressants and anticonvulsants. The time it takes a certain drug to reach the steady level or what pharmacologists call "steady state" depends on how quickly the body disposes of a particular medication. In general, clinical trials of anticonvulsants such as gabapentin (Neurontin) and pregabalin (Lyrica) in neuropathic pain generally show some pain reduction in the first 1-2 weeks of therapy. As the dose is increased over weeks to months, the pain response usually improves. It may take certain antidepressants several weeks (2-4 weeks).

**Please note:** You should check with your personal physician before making any changes to your health care routine.

**For more ideas on "Living with PN", please visit our website: [www.foundationforpn.org](http://www.foundationforpn.org)**

### General Giving

Donate online by visiting our website at [www.foundationforpn.org](http://www.foundationforpn.org), by phone: 1-847-883-9952, or by mail

### Memorial/Tribute/Honor Gifts

Provide a special way to celebrate the memory of a loved one, a birthday, anniversary, wedding, holiday or an occasion of significance for someone you love

### Favors

In lieu of traditional wedding, shower, or party favors consider making a contribution in honor of your guests

### Take Charge

Get creative with fundraising and host your own event! Visit our website to learn more about creative fundraising ideas

### SPONSORSHIP OPPORTUNITIES

- PNRR ■ Young Investigator Awards ■
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### MAJOR GIFTS

- Planned Giving ■ Matching Gifts ■
- Pledged Gifts ■ Stock Options ■

For more information about SPONSORSHIP OPPORTUNITIES and MAJOR GIFTS,

please call 847-883-9942 or email [info@tffpn.org](mailto:info@tffpn.org)

### DONOR/MATCHING GIFT INFORMATION

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 \$50  \$100  \$200  \$500  \$1,000  \$5,000  \$10,000  Other \$ \_\_\_\_\_

Check Please make checks payable to: "The Foundation for Peripheral Neuropathy"

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Credit Card Number: \_\_\_\_\_

Credit Card Expiration Date: \_\_\_\_\_

CUT OUT AND MAIL WITH YOUR DONATION TO:  
 The Foundation of Peripheral Neuropathy  
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## UPCOMING EVENTS

FREE PATIENT SEMINAR

### Living Well with Chemo-Induced Peripheral Neuropathy Seminar

Clinicians from The Foundation for Peripheral Neuropathy Comprehensive Care Clinic at Northwestern will be presenting the latest information on Chemo-Induced PN—its causes, symptoms, tips for nutrition and exercise—so you can live well with this debilitating disorder. You will also hear about the research the Foundation is doing to find better treatments—and eventually a cure!

**DATE**  
December 8, 2010

**TIME**  
6:30pm – 8pm

**LOCATION**  
Wellness Place  
1619 West Colonial Parkway  
Palatine, Illinois 60067

**TO REGISTER**  
Call FPN at 847-883-9942 or  
Wellness Place at 847-221-2400  
Or, send us an email: [info@tffpn.org](mailto:info@tffpn.org);  
please put "Living Well with CIPN" in the subject line.

## 2011

### APRIL 16

Diabetes EXPO, Navy Pier (Chicago)  
Get the latest information on preventing and managing diabetes and its deadly complications to help keep you and your family's health.

### APRIL (TBD)

Day of Wellness, Cancer Wellness Center (Northbrook, IL)

### OCTOBER (TBD)

NBC 5 Healthy Lifestyle EXPO  
Navy Pier (Chicago)

*Check our website for updates on all events.*

YOU CAN SEND US QUESTIONS OR FEEDBACK AT  
**INFO@TFFPN.ORG**  
OR CALL US AT  
847-883-9942

*The Foundation for Peripheral Neuropathy newsletter, FPN News is published two times a year, Spring and Fall. For all who subscribe to our FPN newsletter, you will also receive our, FPN E-news bulletin. To receive the FPN E-news bulletin, please sign up on our website.*



[WWW.FOUNDATIONFORPN.ORG](http://WWW.FOUNDATIONFORPN.ORG)



the FOUNDATION for  
PERIPHERAL NEUROPATHY®

485 Half Day Rd., Suite 200  
Buffalo Grove, IL 60089

[www.foundationforpn.org](http://www.foundationforpn.org)

*Our mission is to dramatically improve the lives of people living with Peripheral Neuropathy.*

*The Foundation for Peripheral Neuropathy will be the catalyst for advancing innovative therapeutic developments and accelerating a cure for painful neuropathies by funding collaborative efforts of leading scientists and physicians. We will strive to raise awareness of peripheral neuropathy through outreach programs to patients, their families and healthcare professionals.*

by neurological disorders. After completing the internship, Ben has a greater appreciation for the amount of time and resources that are required to conduct a proper experiment. Though treatments and cures are in development for some of the most debilitating conditions it takes more than a few months to make them available to patients in need. In fact, the process typically takes several years.

Under the direction of Dr. Ahmet Hoke, Director of the Neuromuscular Division at Johns Hopkins and one of the Foundation's research partners, and his team, Ben worked on peripheral neuropathies (PN) associated with diabetes and chemotherapy-induced PN

(CIPN) caused by Taxol, a common drug used to treat breast and ovarian cancer. He expressed how this journey into basic research has brought him much closer to the clinical aspect of science and how it's applicable to helping patients.

The Johns Hopkins study has been ongoing for four years. In order to participate in the research, Ben learned how to work with mice and rats involved in animal studies and all of the steps needed to keep the research moving forward. When asked about his experience, Cocanougher stated, "It's very rewarding to have the opportunity to see the project through from start to finish."

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