Fast Horses And A Warm Summer Evening......

by Ken Garrison

Quarter horses are bred for speed. They can whiz down that Los Alamitos race course faster than any of their four legged thoroughbred brethren. Typically, thoroughbred races are run over distances from three-quarters of a mile up to a mile and a quarter. On the other hand, Quarters, as these fleet animals are referred to in an abbreviated fashion, usually get their racing competition accomplished in a breathtaking one quarter of a mile.

It is quick, fast and fun. That’s what you can look forward to at PMDF’s LOOKING FOR THE WINNERS CIRCLE evening of excitement at Los Alamitos Race Course on Sunday, September 18th. It promises to be a great summer evening filled with racing, some inside tips on how to pick a winning speedster, and a specially selected buffet dinner and refreshments. To cap it all off, there’ll be some of the best and most interesting items we’ve ever offered at one of our fund raiser auctions, including two tickets on Southwest Airlines, a Panasonic 50” Plasma television, a HEPA Air Purifier, a three-hour cruise in Huntington Harbor aboard the 42-foot yacht Reverie, a high-definition all weather camcorder, skin care gift baskets, exercise equipment, and a handmade necklace. Be sure to look at the auction items listed at the end of this newsletter.

So if you haven’t already gotten your tickets, they’re $125 each for the fast action and fun of an evening supporting the programs of the Parkinson’s and Movement Disorder Foundation. You know how much your support and attendance mean to accomplishing our objectives.

See you in the stands and in the Winner’s Circle.

Looking for the Winners Circle
PMDF Fundraiser
Sunday, September 18, 2011
4:30 P.M.

Los Alamitos Race Course
4961 Katella Avenue
Los Alamitos, CA 90720

$125 per person
60% of your ticket purchase price is tax-deductible

For tickets and information, please call 714-369-7426 or email: vtranpmdf@yahoo.com
Dear friends of PMDF,

There seems to be wide agreement that exercise is a valuable part of the treatment for Parkinson’s disease. In Parkinson’s Disease: A Complete Guide for Patients & Families, the authors state, “We can’t overemphasize the importance of exercise for people with Parkinson’s Disease…We can’t tell whether the physical benefits or the emotional benefits of routine physical fitness are the most significant to our patients. Yet one thing is clear: those who remain physically active benefit on many levels.”

I was diagnosed with early Parkinson’s disease a little over three years ago. The drugs I took for it made a significant improvement in my symptoms, and I made no other changes to accommodate my disease. My doctor recommended a morning program of moderate aerobic exercise and stretching, but I didn’t follow through—getting up at 5:30 to catch the car pool was hard enough without one more time-consuming activity.

As of this week, I am retired. I now have a lot of free time and no car pool. It’s time to start facing my condition, so today I started my exercise program. I’ve been pretty sedentary for the first 62 years of my life, so it’s going to be a challenge to have that discipline, but I intend to demonstrate to myself that the proponents of exercise are right. I’m using Delay the Disease: Exercise and Parkinson’s Disease by David Zid; I’ll have a progress report in a future newsletter.

One other change I’ll be making is getting involved with a support group. I look forward to hearing the stories of other and sharing experiences and suggestions.

I hope you read the article about PMDF’s annual fundraiser, coming up on September 18th. The fundraiser promises to be a lot of fun, and it supports important research (like that described in the article about Dr. Flavia Nery), so come enjoy the evening and support PMDF!

Sincerely,

Mark Wadsworth
PMDF President

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As you may be aware, the PMDF funds clinical research projects that study Parkinson’s disease and other movement disorders. They have fundraisers every year that help to raise the money used for research. So, exactly what is it that they are funding? What is a clinical research trial? I will try to answer these questions and describe how clinical research is helpful and why we need patients to volunteer for these studies.

Basically, research comes in two forms—basic science involving chemistry, cell cultures and animals, and clinical research studies involving people. The clinical research studies most of you are familiar with involve testing a novel medication in people. These studies are usually sponsored by a drug company that has developed the medication and is trying to get the medication approved by the FDA so it can be sold in pharmacies.

There are four phases of studies involving new medications. Phase I is testing safety of the medication. Phase II tests that the medication does what it is supposed to do and helps to determine dosing. Phase III involves larger numbers of people and also looks at the effectiveness of the medication. Phase IV is research using a medication that has already been approved by the FDA and is available for purchase with the proper prescription. Most of these studies have the new medication compared to a placebo or a pill that looks the same but does not have any active ingredients. Depending on how many dosing conditions, you can see the percentages of chance that you may receive placebo. One dose of the study medication compared to placebo—50%. Two doses of the study medication compared to placebo—33% etc. Placebos are very important in clinical research trials and help to determine whether the study drug is actually providing any benefit or not. If you have ever noted that your headache went away within minutes of taking an aspirin, that is a kind of placebo response. The aspirin has not been absorbed into the bloodstream in that short period of time and could not have alleviated the headache that quickly. The placebo effect takes place based upon perception and expectations. If a person expects improvement from taking a pill, some improvement will be seen. A positive response to a placebo can be 60% out of 100%, so you can see it is important to compare the study drug response to the placebo response. Many times the drug company offers an open label study during which the patients will receive the study drug at a known dose following completion of the study with a placebo. This way all of the patients in the study can experience the new medication and the study required for FDA approval can be performed.

There are other clinical research trials that do not involve new medications. These trials can contribute to the greater understanding
of the disorder so that better treatments can be developed. We cannot cure the disease unless we know the cause of the disease. Genetic studies are examples of this type of study. A study looking at SPECT scans can help us to better determine a correct diagnosis. A study looking at a “biomarker” (some kind of disease identifying feature) can help us to diagnose the condition earlier. A study looking at the vestibular system (inner ear) and balance in Parkinson’s disease can help us to understand why patients have trouble with their balance. Other clinical research trials can look at new therapies. The various studies looking at different forms of exercise in Parkinson’s disease are examples of this type of study. As these studies have shown, pretty much any type of exercise is helpful in Parkinson’s disease. Sometimes the clinical research trial involves answering questionnaires. These kinds of studies usually try to understand what it is like to have this disease.

So both basic science and clinical research are important to learn about the disease, develop better treatments for the disease and to find a cure for the disease. How can you get more involved in this process?

Continue to support organizations such as the PMDF which fund clinical research. If you are afflicted with Parkinson’s disease, try joining one of the clinical research trials. Remember not everyone is a candidate for a particular trial. They will ask you questions about your condition before you start. These studies are voluntary; you can stop them at any time. If you are a caregiver, you can accompany your patient to the study or help to answer some of the questions. We can all do our part to advance clinical research in Parkinson’s disease and together we can find a cure.
Dr. Flavia Nery is an Instructor in Neurology at Harvard Medical School and Massachusetts General Hospital in Boston. The PMDF awarded Dr. Nery a $5000 grant in 2010 to study a protein called torsinA that is known to be involved in at least one type of dystonia.

Some individuals with dystonia have mistakes or mutations in the gene that tells the body how to make torsinA. For her PMDF grant, Dr. Nery is working on a newly-identified mutation in the torsinA gene. This genetic mutation often leads to severe symptoms of dystonia that typically begin in childhood.

One aspect of this work that intrigues Dr. Nery is why only some people with this and other mutations in the torsinA gene eventually develop dystonia. This suggests that the genetic mutation is only one “hit,” or one part of the problem in cells that leads to dystonia. In order to develop the disease, people must have another “hit” or problem. Only people with both of the problems—the mutation and some other unknown factor—will actually show the uncontrollable movements characteristic of dystonia. Dr. Nery is interested in conducting research designed to understand the “second hit,” or the unknown conditions that determine whether someone with a mutation in the torsinA gene will go on to develop dystonia.

In her research, Dr. Nery compares cells that have torsinA mutations to those that do not. This research has already produced some interesting findings about what torsinA normally does in the body and how these functions may go awry in individuals with torsinA mutations. One of the normal functions of torsinA is to help cells move to their correct places during development. Cells that cannot find their appropriate locations as the body grows could lead to disorganization of certain brain areas that ultimately manifests as dystonia. Another normal function of torsinA is to help cells get rid of proteins that are not needed or are damaged. Damaged or unwanted proteins can wreak havoc inside cells that could possibly lead to unwanted movements. In time, the research done by Dr. Nery and her colleagues may lead to treatments directed at the torsinA protein that could help it function effectively in people with the disease-causing mutations.

As a graduate student in Brazil, Dr. Nery was inspired to pursue movement disorder research because of the enthusiasm of one of her professors. In 2005, Dr. Nery earned her PhD in Human Genetics and Molecular Biology at the Brazilian Synchrotron Light Laboratory and UNICAMP. That year, her graduate thesis was awarded the “Best PhD Thesis in Biological Sciences in Brazil”. Following postdoctoral work in dystonia research with Dr. Xandra Breakefield at Harvard Medical School, Dr. Nery became an Instructor in the Neurology Department. In her future work, Dr. Nery hopes to learn more about studies in which human beings participate so that she can more thoroughly integrate findings from such studies with her laboratory work on cells.

The PMDF congratulates Dr. Nery on her grant award, and looks forward to hearing about her continued findings on torsinA.

An Interview with Dr. Flavia Nery, PMDF Grant Award Winner

by Mary Ann Chapman, Ph.D.
Auction Items

Because of space reason we are not able to list all the auction items.

Two Southwest Airline Tickets

Three-hour cruise in Huntington Harbor

Rabbit Air HEPA Air Purifier

Wall Gallery Frame

DXG Camcorder

Lasko Outdoor Fan With Remote

Capresso 10 Cup Programmable Coffee Maker
Gift Certificates to Harry Mason Jewelry

Slendertone Abdominal Toner

Two Tickets to Knott’s Berry Farm

Gift Certificate to Best Western

50” Plasma Television
OUR MISSION

To support basic and clinical research into the causes, treatments and cures for Parkinson’s disease and other movement disorders such as dystonia, myoclonus, spasticity, and tremor.

The Parkinson’s and Movement Disorder Foundation is committed to working with other organizations that have similar philosophies in an effort to bring together expertise from both basic and clinical science perspectives.

We are dedicated to enhancing the quality of life for those who suffer from movement disorders and their families, through research, education, and community outreach.