

No. 2/September 2011

MULTIPLE SCLEROSIS



THE MISUNDERSTOOD DISEASE

As his mother battles multiple sclerosis, **Dr. Timothy West** strives to improve the lives of those living with the disease

New research

Making progress through new studies and clinical trials

Phil Keoghan

Rides a bike across America to raise money for MS research

Focus on wellness

Everyday tips for a healthier lifestyle

CHALLENGES



FAMILY TIME
Devrha, diagnosed with MS in 2008, and her two young daughters enjoy a musical moment together.

PHOTOS (TOP AND BELOW): AMELIA DAVIS

Over 2 million people worldwide live with the chronic and unpredictable disease, multiple sclerosis.

Breaking down the disease

Every hour someone is newly diagnosed with multiple sclerosis, a chronic, unpredictable disease of the central nervous system, which includes the brain, optic nerves and spinal cord.

What causes MS?

It's not clear. Studies suggest that genetic factors are involved, but there is no evidence that MS is directly inherited. Though MS isn't contagious and is rarely fatal, it is a life-altering disease and the most common disabling disease of young adults.

Who gets MS?

Two to three times more women than men are diagnosed with MS, but in men, the disease often takes a more aggressive course. Most people are diagnosed between the ages of 20 and 50. MS

occurs in most ethnic groups. In the US, at least 400,000 people have the disease.

What are the symptoms?

MS can cause loss of balance, poor coordination, slurred speech, tremors, numbness, weakness, fatigue, problems with memory and concentration, paralysis, blurred vision, blindness, pain, bladder problems, sexual dysfunction and more. These problems may be permanent or come and go. They can vary from person to person and from time to time in the same person. They are the result of the immune system attacking its own myelin, the protective covering that surrounds nerve fibers. Loss of myelin and their underlying nerve fibers interferes with the flow of information within the brain and between the brain and the rest of the body.

What can be done?

Medications that have been



“Every hour someone is newly diagnosed with multiple sclerosis.”

shown to “modify” or slow the course of MS have been approved by the FDA. There are also multiple medications and strategies to address the disease's many symptoms.

What is the National MS Society?

“The Society is a driving force in MS research, treatment and support services for people affected by MS,” says Dr. Timothy Coetzee, chief research officer. “Through its 50-state network of chapters and the efforts of volunteers, donors, researchers and health care professionals, the Society provides outreach, education, advocacy and support to over a million people annually while funding more than 325 research projects around the world.”

To learn more information go to nationalMSSociety.org.



WE RECOMMEND



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How experts are working to uncover the cause of MS and find more effective treatments

“Researchers are working to unravel the genetic basis for susceptibility to MS.”

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Learn what's available to slow the progression of the disease

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Mobility is among the most common symptoms associated with MS

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MS doesn't have to slow you down.

Find out about **The Walking Pill.**

We know that multiple sclerosis (MS)
can make your favorite daily
rituals, like walking your dog,
more challenging.

But today there's **AMPYRA**[®]
(dalfampridine), an FDA-approved
oral medication indicated to improve
walking in patients with MS. This
was demonstrated by an increase
in walking speed.

The average increase in walking speed
for those who responded to AMPYRA
was roughly 25%. That's why we call it
The Walking Pill.

AMPYRA does not work for everyone.

Talk to your doctor to see if AMPYRA is right for you.

TheWalkingPill.com

1-888-881-1918

IMPORTANT SAFETY INFORMATION:

Talk to your doctor about AMPYRA to learn if it is right for you. Do not take it if you've ever had a seizure or if you have certain types of kidney problems as this may increase your risk of seizure. Tell your doctor if you have kidney problems.

AMPYRA may cause serious side effects including kidney or bladder infections. The most common side effects are urinary tract infection, trouble sleeping (insomnia), dizziness, headache, nausea, weakness, back pain and problems with balance. Tell your doctor if you have any of these side effects that bother you or do not go away.

This is not the full safety information. For more information, please refer to the Medication Guide on the next page. This important safety information is not meant to replace discussions with your doctor.

For more information call toll-free 1-888-881-1918

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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AMP823

ampyra[®]
(dalfampridine) **10 mg**
EXTENDED RELEASE TABLETS



MEDICATION GUIDE FOR AMPYRA® (am-PEER-ah) (dalfampridine) Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA.

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is the most important information I should know about AMPYRA?

AMPYRA can cause seizures.

- Your chance of having a seizure is higher if you take too much AMPYRA or if you have kidney problems.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See "How do I take AMPYRA?"

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

What is AMPYRA?

AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

Who should not take AMPYRA?

Do not take AMPYRA if you:

- have ever had a seizure
- have certain types of kidney problems

What should I tell my doctor before taking AMPYRA?

Before you take AMPYRA, tell your doctor if you:

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements. Know the medicines you take.

Keep a list of them and show it to your doctor and pharmacist when you get a new medicine.

How should I take AMPYRA?

- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine)

What are the possible side effects of AMPYRA?

AMPYRA may cause serious side effects, including:

- Kidney or bladder infections
- See "What is the most important information I should know about AMPYRA?"

The most common side effects of AMPYRA include:

- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store AMPYRA?

- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

Keep AMPYRA and all medicines out of the reach of children.

General Information about the safe and effective use of AMPYRA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

For more information, go to www.AMPYRA.com or call 1-800-367-5109.

What are the ingredients in AMPYRA?

Active ingredient: dalfampridine (previously called fampridine)

Inactive ingredients: colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

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This Medication Guide has been approved by the U.S. Food and Drug Administration.

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NEWS



SUPPORT SYSTEM
LEFT: Judy (seated right),
diagnosed 1982. RIGHT:
Tiffany, diagnosed 2004.



How to improve your quality of life

■ **Question:** What is the most effective way to battle MS?

■ **Answer:** Early treatment is your best bet for delaying disease progression.

There are ways to improve the daily activities in your life that don't involve medication.

Get educated. The more you know about MS, available treatment strategies and community resources, the more empowered you'll feel to handle the unpredictable changes and challenges of MS.

Create your team. Find a physician who will partner with you to manage the disease and engage other medical professionals in a coordinated and collaborative effort to treat your symptoms and optimize your quality of life.

Start treatment early. The currently available disease-modifying medications are most effective



Rosalind Kalb, Ph.D.
Vice President,
Professional
Resource Center

early in the disease, when you may be feeling fine but the disease is active in ways that you cannot see or feel. Early treatment is your best bet for delaying disease progression.

Focus on wellness. The healthier you are, the better equipped you'll be to manage your MS. Exercise, a healthy, well-balanced diet, good stress management techniques, regular checkups and health screening tests are important for everyone with MS.

Pay attention to your mood. Depression is one of the most treatable symptoms of MS, so discuss changes in your mood with your health care professional.

Think positively but be practical. Planning for all the "what ifs" (I can't work...I can't walk...I can't drive) is the best way to feel prepared for the unpredictable. With strategies in mind to deal with possible changes down the road, you can focus on enjoying the here and now.

Be flexible. The key to living fully with MS is your willingness to do things differently, using assistive technology to help you get where you want to go and do what you want to do.

Connect with others. Whether in person or online, getting together with others to share ideas, feelings and solutions can help you feel less alone while facing the challenges of MS.

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NEWS IN BRIEF

Current treatments

There is no cure for MS, however there are many options to help better manage the disease.

There are now eight disease-modifying therapies, including one oral treatment, available to slow the increase in disability and reduce the frequency and severity of exacerbations. Severe exacerbations (also called attacks, flare-ups and relapses) are most commonly treated with corticosteroids.

MS symptoms, which can range from mild to severe, can often be successfully managed with medications, self-care techniques, rehabilitation and the use of devices such as mobility aids. The first oral therapy specifically developed to treat an MS symptom is now available to assist people with their walking issues.

Rehabilitation programs—with a physical or occupational therapist, speech/language pathologist or cognitive specialist, among others—focus on restoring function. They emphasize fitness and energy management, while addressing mobility, speech, memory and additional complications.

Giving hope

With current research and emerging treatment options, there are many reasons to be hopeful about the future of MS.

The complexity of MS requires a comprehensive approach to research. It involves supporting individual researchers along with multinational academic and commercial research teams in projects that include discovery research to advance knowledge; translational research to move initial academic and biotech research discoveries toward commercial development; and clinical trials to advance breakthrough treatment. This multifaceted approach can change the lives of people living with MS.

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INSIGHT



EXPERT OPINIONS

Dr. Timothy Coetzee and Dr. Nicholas G. LaRocca provide insight into current studies and physical challenges associated with MS.



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Programs, National MS Society

The importance of clinical trials

Anyone who's ever taken medicine has experienced the benefits of clinical trials. Today we have therapies that largely help with the immune attacks in MS. Now we need to stop disease progression and restore function to the nervous system.

Critical issues are emerging in our ability to conduct these trials for MS, which must be addressed:

- The number of trial patients is diminishing; we're supporting novel trial designs needing fewer participants.

- Determination as to whether a therapy is protecting or repairing the nervous system; we're developing better outcome measures for clinical trials.

- Expensive trials; we're mitigating risk in early-stage therapeutics through our Fast Forward drug development subsidiary.

There have never been so many opportunities to make breakthroughs in MS.

The life-changing impact of mobility

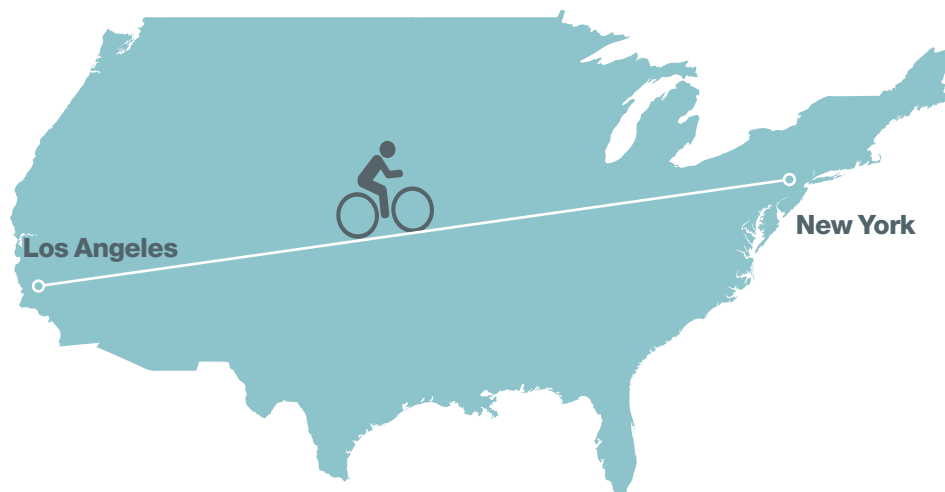
Imagine having to miss a major personal event, move from your home or stop working because of problems with something most people take for granted—walking. A recent Harris survey indicates that for two-thirds of people with MS, mobility is a significant challenge.

Trouble walking can lead to a host of social, physical and emotional problems. Most people with MS say that walking problems have adversely affected their financial security, everyday tasks, social life and self-esteem.

Difficulty walking can also lead to falls and serious injury, and walking difficulty can trigger feelings of depression and discouragement for people with MS and their families. Fortunately, help is available if doctors and patients take the opportunity to discuss walking problems and explore the array of therapeutic and rehabilitative solutions available today.

Question: How can people contribute to advancing MS research and supporting advocacy?

Answer: Get involved with MS fundraising events in your local community.



The amazing research champion

Phil Keoghan, host of "The Amazing Race," not only pushes the show's contestants to the limits — he also pushes himself to the limit by living by the mantra "No Opportunity Wasted."

Following a near-death experience at 19, Keoghan created a "life list" of things he wanted to do before dying — one item on that list included biking across America.

In 2009, Keoghan partnered with the National MS Society and rode his bike from Los Angeles to New York. Working alongside the organization, he turned the ride into a national fundraiser, bringing in over \$500,000. He also produced a documentary, "The Ride," which chronicled the trip and raised thousands

more for MS research and programs.

This year, Keoghan has partnered with the Society again to launch NOW: An MS Research Revolution, a five-year, \$250 million research fundraising commitment. Its goals are trifold: Stop the progression of MS. Restore functions lost to MS. End MS for future generations.

"There's a chapter in my book about the incredible feeling you get from helping someone," Keoghan said. "Whatever you give, you get back tenfold. That's been my experience working with the Society."

Keoghan is also the first official MS Research Champion and has created a pro women's cycling team which races to build MS awareness.



Phil Keoghan
Host, "The Amazing Race"
PHOTO: BRIAN HODES, VELOIMAGES.COM



"Whatever you give, you get back tenfold."

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NEWS

What's new in the pipeline

Research is essential to finding a cure

Researchers are working to unravel the genetic basis for susceptibility to MS; predict an individual's pattern of MS; identify biomarkers that may help determine individual treatment; and find better therapies for the disease and its symptoms.

A few of the many avenues that are receiving attention:

- Gender differences that may lead to new treatment possibilities.
- Robotics to retrain the brain in order to improve walking.
- Vitamin D and its relationship to MS susceptibility and the disease process.
- Chronic cerebrospinal venous insufficiency (CCSVI), a reported blockage in blood drainage from the brain and spinal cord, which may contribute to nervous system damage in MS.



MS TREATMENTS. Making a mark in the progress of research

PHOTO: ALCIA BRAGA

- New tools to speed up and improve clinical trials.

Also under investigation: new oral medications (currently the majority of disease-modifying therapies have to be injected); immune factors that may signal new opportunities for turning off attacks or protecting brain cells;

marijuana to alleviate pain and spasms; a molecule called Axin2 that may be essential in the repair of myelin; and possible connections between infectious agents that might serve as triggers of MS.

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NEWS IN BRIEF

Fast Forward

Realizing that translational research is one of the most vulnerable links in speeding up needed treatments for people with MS, the Society established Fast Forward in 2007 as a wholly owned subsidiary to fast-track research into commercial MS therapies and treatments.

Fast Forward is currently supporting projects in seven young biotech firms, one of which has already leveraged that funding to secure pharmaceutical company support for phase 1 clinical trials. It has also entered into a collaborative research project with a major pharmaceutical company targeting neural repair and protection, funding seven drug development projects to date. For more info go to fastforward.org.

working to change

MS **MORE**
LIVE

Revolutionizing the management of multiple sclerosis for patients and the ones who care for them through innovations in science.
That's our commitment to the MS community.

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INSPIRATION



PATIENT CARE
Dr. Timothy West chats with his patient at the Cleveland Clinic.
PHOTO: CHRIS ANDRADE
CASHMAN PRODUCTIONS

A mother's struggle inspires her son to make a difference

When her MS forced Abby West of Salt Lake City, mother of five and grandmother of eight, to leave a job she loved as activities director in a long-term care facility, she "cried for seven years," says Abby. "One of the hardest things about MS was giving up my job after my walking began deteriorating at lightning speed and I seemed to get one bladder infection after another. My memories of giving service and love to people with disabilities are the most glorious of my life."

Her MS did have one remarkable benefit: It inspired her son Timothy to become a neurologist and MS specialist. Abby was diagnosed with MS in 1992, after 15 years of symptoms that started when she was pregnant with Tim. "On a not-so-remark-

able day early in my teenage years, my mother told me she had MS. I had no idea what that was, or what it meant. I only knew she seemed very upset," he recalls. Still, Abby appeared invincible until just before Tim's college graduation, when she experienced an exacerbation impacting her spinal cord so severely that she has used a wheelchair ever since.

Career path

Inspired by his mother's struggle and seeking to learn more about MS, Dr. West took a year off from medical school to perform clinical research at the University of California, San Francisco. This work became the turning point in his decision to become a neurologist rather than a pediatrician. A fellowship took him back to UCSF in 2010, after which he accepted the directorship of a brand-new MS program at



"I want to build the center I wish had been available for my mom."

Dr. Timothy West

the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas. "We are creating a place where patients with MS can get all the care they need in one place," says Dr. West. "I want to build the center I wish had been available for my mom."

Every effort counts

Four years ago, Abby's depression over her loss of mobility was at a low point. Karey Spransy, her niece, volunteered to be Abby's personal trainer. Karey had ridden and been team captain in the Bike MS event in Logan, Utah. "She helped me find a bicycle I could hand-crank," Abby says. "It was something I did on my own, something I didn't know I could do, and my tears stopped. I've ridden in Bike MS ever since." Her son will now start his own cycling team at his hospital where they will participate in the local Bike MS event.

"My mother is one of the kindest and most understanding people I know and she inspires love in everyone who meets her," says Dr. West. "One gentleman, a complete stranger initially, built her a three-wheel seated bike for free to make it easier for her to be a part of the Bike MS team."

MS has taken a huge toll on Dr. West's parents who have been together through ups and downs for 37 years. "They have gradually eaten through all of their life savings in an effort to preserve my mom's quality of life. Multiple sclerosis is a terrible disease" says Dr. West, "but a knowledgeable, caring and diligent physician can make an enormous difference. I have seen this both as a neurologist and as a son. This fact motivates me each time I see a patient."

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Close to home

✧ As a child, Timothy watched his mother struggle with an incurable disease. His love for his mother and passion to help people with MS led him to become one of the most well-respected doctors in Las Vegas. As a caring son and through his professional career, Timothy continues on his road to success by helping every single patient that walks through his door.

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