

Get Well, Spend Less

How to save money through the many patient assistance programs that offer help with treatment costs. BY KURT SAMSON

In September 2010, David Watson—who lives in Montgomery, AL, and had been suffering from severe fatigue—got his lab test results back. The news was not good. Watson was told that he had chronic myelogenous leukemia, a genetic form of blood cancer that can lead to a number of neurologic problems as it progresses.

With available treatment options, many patients survive for five years, but Watson's doctor, Robert A. Avery, M.D., of the Southeast Cancer Network in Montgomery, told him that far better results were being reported in patients taking a drug that had just come on the market: nilotinib, marketed under the brand name Tasigna. Watson went home with a prescription.

Then came the sticker-shock. The Wal-Mart pharmacist informed him that a one-month supply would cost around \$12,000.

"I felt hopeless," says Watson. "Living only on Social Security, I could never afford it."

Fortunately, a well-informed nurse at his doctor's office told him about an organization that might help: Patient Services Incorporated (PSI), a non-profit medical assistance group in Midlothian, VA. She even filled out the application for him and

obtained the necessary signatures from his physician.

"I heard back from PSI fairly quickly. I have prescription coverage under Medicare and Blue Rx, Blue Cross and Blue Shield's program. But PSI pays for the balance of what Medicare and Blue Cross don't. They'll do it for three years, and after that I can reapply. As it is now, I don't pay anything at all," Watson says.

Another unanticipated benefit, he adds, is that the extra financial help allowed him to pass back through the so-called Medicare Part D "donut hole."

"Once you've hit Medicare's prescription reimbursement limit, you fall through the donut hole and have to pay all drug expenses out of your own pocket," Watson explains. The current Medicare threshold is \$2,840. "But then once you've paid



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a certain amount yourself, you emerge from the hole and Medicare kicks in again. Today, I pay just \$2.50 for each of my prescription drugs, except for Tasigna.”

KNOW THE OPTIONS

Being diagnosed with a neurologic disease is difficult enough, but the cascade of costs associated with treatment and care can be overwhelming, especially for patients without good health insurance.

An estimated 100 million Americans can't afford their medications or are struggling and making sacrifices to afford them. The current economic slump and anticipated cuts in federal assistance programs is a concern for many patients who rely on government help to pay for treatment and medicine.

The economic downturn is also being felt by major organizations that rely on donations to provide assistance to neurologic patients who cannot afford treatment. Earlier this summer, the American Health Assistance Foundation announced that it was discontinuing its Alzheimer's Family Relief Program, which had provided direct financial assistance and resources for Alzheimer's disease patients and their caregivers. The program had awarded \$2.3 million since its start in 1988.

Yet a number of private and nonprofit programs like PSI are still going strong. Sponsored by non-profit advocacy organizations, patient groups, and pharmaceutical companies, these programs offer an array of options to help offset the cost of treatment and daily care.

Medicare and Medicaid remain the first line for treatment coverage, and many states (see map, page 61) also have assistance programs. But for some patients, the available funding falls short due to increasing prices of medications and the incremental need for care due to the progressive nature of many neurologic diseases. Moreover, some of the products and services for daily challenges faced by patients are not covered, such as adaptive renovations to accommodate disabilities, transportation assistance, and people to help shop, clean, and cook.

Government experts estimate that around 60 percent of seniors who qualify for federal and state assistance programs are not enrolled in such programs, so make sure that you know what these programs are and whether or not you qualify for enrollment.



DAVE WATSON
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Whether it's help paying for prescription drugs, health care, utilities, or other basic needs, the National Council on Aging (NCOA) offers one of the most comprehensive services on the Internet, providing links and contact numbers covering a range of issues familiar to anyone with a neurologic condition. As of Sept. 9, 2011, the group has helped almost 3 million people locate over \$10.4 billion worth of benefits.

According to the NCOA, millions of older patients who are eligible for existing federal, state, and local assistance programs fail to take advantage of them. These range from heating and energy assistance to prescription savings programs and income supplements.

“There are many public programs available to seniors in need if they only knew about them and how to apply for them,” according to the NCOA patient assistance Web site (benefitscheckup.org/about.cfm).

The BenefitsCheckUp service is an all-inclusive service on the Internet for locating programs for seniors with limited income and resources. It lists more than 2,000 public and private benefits programs in all 50 states and the District of Columbia. These include programs that can help pay for prescription drugs, energy assistance,

financial aid, legal help, transportation, and in-home services.

Another often-overlooked resource is the federal Hill-Burton Program. Even though it officially ended in 1997, some 300 hospitals and health care facilities are still obligated to provide free or reduced-cost care to those who cannot otherwise afford it. Patients generally must be at or below the federal poverty limit, but they may be eligible even if their income is as much as two times the current Department of Health and Human Services “poverty” benchmark (or three times higher for nursing home assistance).

HELP WITH PRESCRIPTIONS

The cost of medications for individuals with neurologic disorders can be astronomical. To make matters worse, these drugs typically have to be taken as directed for the rest of a patient's life. We've all heard the stories of people who have had to decide between buying food or medications; the Partnership for Prescription Assistance (PPA) is one of many programs that has stepped in to help. In North Carolina alone, the organization has helped some 262,000 patients find free and low-cost medications.

The **Partnership for Prescription Assistance** helps low-income patients without prescription coverage **get the medicines** they need.

In fact, PAF represents patients on a number of levels. Although it is very active in the health reform arena, it has also helped millions of patients by providing professional case management services for patients with chronic and disabling diseases who have difficulty getting access to health care. The group helps solve medical debt problems as well as employment-related issues, without any cost to the patient.

The nonprofit organization PatientAssistance helps patients who can't afford prescription medications find company-sponsored assistance programs. NeedyMeds, another non-profit, helps people who cannot afford medicine or health care costs, and has a special site for Alzheimer's disease assistance.

FOUNDATION SUPPORT

Many disease-specific foundations offer help in various forms for those who cannot otherwise afford it. For example the Muscular Dystrophy Family Foundation offers adaptive equipment to individuals and families affected by any one of 40 neuromuscular diseases.

The Multiple Sclerosis (MS) Foundation offers up to \$1,000 for items such as wheelchair ramps that improve the quality of life for those with MS.

Spinal Cord Opportunities for Rehabilitation Endowment (SCORE) helps individuals with spinal cord injuries (preference given to young people injured while participating in sports) to fund items such as vehicle adaptations. The Travis Roy Foundation offers grants (ranging from \$4,000 to \$7,500) to paraplegics or quadriplegics paralyzed due to spinal cord injury.

The Brain Tumor Foundation for Children and the group Play for 4 both provide financial assistance and information for families of children with brain and spinal cord tumors. Play for 4 also provides financial assistance for adolescents who have suffered traumatic brain injuries during athletic activities and those responsible for the expenses associated with their care. This financial assistance may be used to cover medical expenses both in and out of the hospital, rehabilitation and therapy expenses, and costs related to bringing patients home and ensuring they have the equipment and care needed to successfully recover. These funds may also be used to for special educational needs.

PHARMACEUTICAL COMPANY ASSISTANCE

Many major pharmaceutical companies have prescription assistance programs for disadvantaged individuals who must take brand name as opposed to generic medications. The list of these sponsored programs is long, but it includes many drugs taken by patients with neurologic disorders. For example, Pfizer offers reduced-cost Neurontin for treating seizures under its Pfizer Pfriends program. Always inquire if a company has a program by asking your physician or pharmacist or by checking a company's Web site, where such information is typically featured prominently on their home page with contact numbers and on-line application forms.

GlaxoSmithKline's Bridges to Access program offers several patient assistance options to meet a variety of patient needs and provides GlaxoSmithKline prescription medications at little or no cost for qualified applicants.

Biogen Idec and Elan Pharmaceuticals, Inc., sponsor ActiveAccess, a service to help MS patients find the best financial assistance and insurance solutions for treatment. ActiveAccess will investigate benefits to clarify any coverage options and provide insurance counseling to help obtain adequate coverage. The service also offers \$10 co-pay programs with no income requirements and no enrollment time limit for eligible patients, help with infusion treatment costs, free medications

for eligible patients in need, and help finding assistance through various charitable organizations.

Astrazeneca's RxAssist is a comprehensive directory of private and public sector programs to help individuals pay for medications and other services related to their medical condition. Abbott and Eli Lilly also have programs, as do many smaller drug manufacturers. Pfizer offers Helpful Answers, a group of assistance programs for the uninsured and underinsured who need help getting Pfizer medicines. They either provide the medications free or at a discount.

Boehringer Ingelheim offers assistance programs for patients who need to obtain free or reduced-cost medications. In 2009 alone, it helped more than 47,000 eligible patients received help from pharmaceutical companies offering assistance programs through its RxHope Web site. Patients can



MICHELLE BROVITZ used the GiveForward Web site to raise \$10,000 to help buy a high-tech nerve stimulation "exercycle" that improved her multiple sclerosis symptoms almost immediately.



search for their medications and possible help, but their medical provider must file the application.

SOCIAL MEDIA FUNDRAISING

One of the more novel approaches to helping patients get money for treatment is Chicago-based GiveForward, a Web-based social media platform used by patients and caregivers to solicit donations from friends and family members. To date, users have raised over \$6 million.

Michelle Brovitz, who was diagnosed with relapsing-remitting MS while in grad school but whose illness has advanced into the secondary progressive stage, used GiveForward to raise enough money to purchase a special nerve stimulation stationary “exercycle” that helped actor and advocate for paralysis patients, Christopher Reeve, who died in 2004.

“I have been declining slowly but steadily since about 2000. I went from being a normally functional young adult to needing a cane and then a walker, which I still use. As a result, I am no longer able to work,” according to her testimonial on the organization’s Web site. (The GiveForward staff investigates all applicants to make sure they are legitimate.)

For 15 years, Brovitz says, she was offered little hope of improvement.

“My doctors told me, and this is a direct quote: ‘There’s nothing more we can do for you,’” she says.

Then a specialist at Johns Hopkins Hospital, in Baltimore, MD, told her that some patients in her condition were getting improved mobility using the functional electrical stimulation exercycle.

Unfortunately the equipment costs almost \$15,000, so she used GiveForward to launch a fundraising campaign and raised \$10,000 in just 12 weeks. She was then able to purchase the bike with an additional \$5,000 of her own. Although she was told not to expect results for at least three months, Brovitz says she began experiencing slight improvements almost immediately.

“It’s not easy money; it took a lot of work on my part. But it is amazing how quickly I was able to raise the money,” she says. “I recommend GiveForward to anyone who needs financial help. It’s not a free ride, but it is a free site.”

ALWAYS ASK A NURSE

David Watson’s treatment has been an unqualified success. His leukemia is now in complete remission, and he hasn’t broken the bank.

“My advice to other patients who find themselves in the same position as I was in September 2010 is to ask their doctor about assistance programs,” says Watson.

“And always ask a nurse.”

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Resources for Saving Money on Care

- ▶ ActiveAccess (Biogen Idec and Elan Pharmaceuticals, Inc.)
msactivesource.com/cost-and-insurance.xml
800-456-2255
- ▶ Brain Tumor Foundation for Children
braintumorkids.org 404-252-4107
- ▶ Bridges to Access (GlaxoSmithKline)
bridgestoaccess.com 866-728-4368
- ▶ GiveForward
giveforward.com 312-322-1200
- ▶ Helpful Answers (Pfizer)
pfizerhelpfulanswers.com 866-706-2400
- ▶ Multiple Sclerosis Foundation
support@msfocus.org
msfocus.org 888-673-6287
- ▶ Muscular Dystrophy Family Foundation
mdff.org 317-923-6333 or 800-544-1213
- ▶ National Council on Aging (NCOA)
benefitscheckup.org 202-479-1200
- ▶ NeedyMeds
needymeds.org
needymeds.org/resourcepages/alzheimers.htm
Does not handle telephone inquiries
- ▶ Partnership for Prescription Assistance
pparx.org 888-477-2669
- ▶ PatientAssistance.com
PatientAssistance.com 888-788-7921
- ▶ Patient Advocate Foundation
patientadvocate.org (800) 532-5274
- ▶ Play for 4
playfor4.org
splitt@playfor4.org Does not handle telephone inquiries
- ▶ RxAssist (AstraZeneca)
rxassist.org
info@rxassist.org Does not handle telephone inquiries
- ▶ RxHope (Boehringer Ingelheim Patient Assistance Programs)
rxhope.com 800-556-8317
- ▶ Spinal Cord Opportunities for Rehabilitation Endowment (SCORE)
scorefund.org
questions@scorefund.org 323-655-8298
- ▶ Travis Roy Foundation
travisroyfoundation.org 617-619-8257