
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

JULY 2008

The Derby City Chapter of the National Spinal Cord Injury Association Network- Serving Kentuckiana.

Message From the President

Dear Members & Friends-

THERE WILL NOT BE A MEETING IN JULY.

August's meeting will be held at Frazier Institute, 220 Abraham Flexner Way, 10th floor dining room, Louisville.

-David Allgood

From New Mobility.com

GETTING EQUIPMENT GETS HARDER By Tim Gilmer

Wheelchair users are finding out that getting the durable medical equipment they need—and getting it when they need it—is getting harder and costlier. Restrictive documentation policies as well as outdated “in-the-home” language that governs claims decisions in the Centers for Medicare and Medicaid Services are creating hassles for DME dealers and consumers. What’s worse, power wheelchair reimbursements made by Medicare—already reduced by 27 percent in January 2007, will be reduced by another 19 percent on July 1 due to Medicare’s national competitive bidding program. Since private insurance companies follow CMS’ lead, these new policies portend a growing nightmare of denials, delays, red tape, and economic hardship for DME dealers and users alike.

When Abbie Freedman, of Santa Rosa, Calif., was paralyzed at age 39 due to a T5 spinal cord injury, she was immediately covered by MediCal. A year and a half later, because MediCal does not allow anything more than subsistence funds in the bank, she was switched to Medicare. She used three wheelchairs in the next 22 years, and Medicare picked up the costs. Now in her early 60’s, with deteriorating shoulders, Freedman was advised to have corrective surgery, but her personal physician, knowing how difficult recovery can be, advised against it. Instead, he prescribed specialized

therapy and a new power wheelchair.

Freedman ordered an iGLIDE, manufactured by Independence Technology, and was told by IT that Medicare would cover it. Anxious to get on with saving her shoulders, she paid for it out of her own pocket, then filed a claim for reimbursement for Medicare. She received the chair in September 2004 but was surprised when her claim for reimbursement was denied. “I’m not sure I would have ordered it had I known Medicare wouldn’t pay,” she says. “\$6,230 is a lot of money.”

The Medicare denial stated: “This item cannot be paid without a new, revised, or renewed certificate of medical necessity.” Freedman then resubmitted a new CMN and her appeal was approved in March 2005, but no reimbursement was issued. Later she received a letter dated June 28, 2005 from a Medicare administrator in response to her appeal, stating, “If you paid any amount to this provider for this service, Medicare will pay you back the amount you paid. To get this payment, bring or send to this office three things: 1. A copy of this notice; 2. Your supplier’s bill; 3. A receipt or other proof that you have paid this bill.”

“At that time, I submitted the three required documents,” says Freedman. “Since then, I have made several attempts to get this reimbursement from Medicare, both written and by phone, only to get a runaround, no response, or one that is irrelevant,” she says.

The latest runaround occurred in August 2007, when she was told by CMS that she would receive reimbursement by CMS’ contracted carrier—Noridian Administrative Services, of argo, N.D., but she would have to contact them directly. She did, and was told she had to fill out another form. “It was an original claim form! After

(Continued On Page Two)

Table of Contents

President’s Message.....	1
Is Getting Equipment Getting Harder?.....	1
Calendar.....	3
For Sale/The Standing Chair.....	5

Derby City Area Chapter
of the
National Spinal Cord Injury
Association

ABOUT THE ORGANIZATION

The Derby City Area Chapter of the N.S.C.I.A. is a membership organization for individuals with spinal cord injuries, their families, and health professionals. Founded in 1984 as a Charter Member of the N.S.C.I.A., it was incorporated under IRS Section 501 (c) 3 as a not for profit organization. The Board of Directors consists of the Officers, Past President and the Board Members At Large.

OFFICERS

PRESIDENT

David Allgood - (502) 589-6620

VICE PRESIDENT

Adam Ford - (502) 425-2206

TREASURER

Tom Stokes- (502) 957-5865

LIAISON TO FRAZIER REHAB INSTITUTE

Jill Farmer , CTRS—(502) 582-7618

FUNDRAISING CHAIR

Betty Perry—(502) 647-0368

CORRESPONDING SECRETARY/WEB MASTER

Michael Feger- (502) 647-0368

PAST PRESIDENT

Adam Ford- (502) 425-2206

BOARD MEMBERS AT LARGE-

Mike Perry

Kelly Young

NSCIA
DERBY CITY CHAPTER
NEWSLETTER

Editor- Barbara Davis

Contributor- David Allgood

Visit Our Website at
www.DerbyCitySpinalCord.org

**The Derby City Area Chapter Newsletter is
brought to you through the generous support of
Frazier Rehab Institute**

GETTING EQUIPMENT HARDER, CONT'D

nearly four years, they sent me back to square one. The system is a joke, but it's not funny."

In December 2007 Freedman received another letter from Medicare stating that the iGLIDE would not be covered. "I'm getting worn down. If it were less money, I would just give up. I can't tell you how many phone calls and letters I've sent, and you never get the same person. But I'm not giving up. It's not only the money, it's the principle. They keep telling me I'm entitled to reimbursement, but it's going on four years, and I haven't seen a dime.

On May 15, 2007, Sue Montgomery met with her local durable medical equipment dealer and ordered a Quickie Ti Ultralight as a replacement wheelchair. Six weeks later, Montgomery, of Knox, Pa., called and discovered that the person handling the paperwork had accidentally misplaced the paperwork, so it was re-sent. On July 17, Montgomery learned that her insurance company had denied her claim: the wheelchair was deemed "not a medical necessity."

Montgomery, who has severe bilateral osteoarthritis, had filed documentation of medical need by her orthopedic surgeon along with her need as an active lifestyle wheelchair user with a full-time job. Her medical records established that she had undergone 11 failed reconstructive surgeries and had used a wheelchair for 15 years. Understandably upset, she appealed the denial, which set in motion a series of appeals and denials—she appealed three times—until she finally received a letter of approval on October 9, followed by a shipment of the wheelchair on November 14. But the wheelchair that arrived had no brakes, no cushion, no anti-tip bars, and was the wrong size seat depth. Montgomery refused the chair. A different chair arrived on December 7 but still had the wrong seat depth. Finally, on January 4, 2008, the seat depth issue was solved. The list price on Montgomery's Quickie Ti was nearly \$5,700, definitely on the high side.

In her research, Montgomery discovered that had she been covered by Medicare (or if her private insurer would have allowed it), she might have been able to sign an Advanced Beneficiary Notice giving her the option of paying the difference between what the Medicare codes allow for a given type of wheelchair and the actual cost of the product. Under an ABN, she would have been allowed \$2,986, and she would have paid \$2,641 out of pocket. However, Montgomery's private insurance did not allow an ABN (see www.wheelchairjunkie.com/abn.html for an article on ABNs). Fortunately, since Montgomery won her appeal on the third try, she got a much better deal, paying only an out-of-pocket deductible of a few hundred dollars. Although the overall purchase price was high, her portion was minimal. Not all insurance companies would have covered as much.

(Continued on Page Four)

Refrigerator Calendar

***2008**

JULY

7th - Elderly & Disabled Advisory Council Meeting.
Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.

21st - Derby City Chapter SCIA WILL NOT MEET THIS MONTH.
Mon

19th - Metro disAbility Coalition Meeting; 3:15 p.m.
Sat Urban County Government Center; Barrett Avenue; Louisville

AUGUST

4th - Elderly & Disabled Advisory Council Meeting
Mon 1:00; TARC; 1000 W. Broadway; Board Room.

18th - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute
Mon 220 Abraham Flexner Way; Louisville; 10th Floor dining room.

16th - Metro disAbility Coalition Meeting; 3:15 p.m.
Sat Urban County Government Center; Barrett Avenue; Louisville

SEPTEMBER PICNIC
INFORMATION FORTHCOMING IN
FUTURE ISSUES

For More Information Call
David Allgood at 502-589-6620

EQUIPMENT, CONT'D

“The most important thing I did in the final appeal was document my need for an ultra-lightweight. I documented 29 years of stress on elbows, wrists, and shoulders from using crutches and wheelchairs. We also stressed the need to maintain my independence not only in my active lifestyle but in my daily living skills in the home.”

Walter Reynolds, 57, injured at the T9 level in 1970, feels fortunate to be able to live on acreage in central California. He moved to the Santa Maria area in 1980 and not long after landed a good job, where he has been promoted over the years, enabling him to purchase property in a secluded canyon-like area. His lifestyle would be physically demanding for anyone, but for a wheelchair user, appropriate adaptive equipment is critical. He has a long gravel driveway to maintain, a well, a Septic system, and several outbuildings, and he tries to do as much as possible himself.

Problems with shoulder wear and tear from decades of wheeling resulted in rotator cuff surgery, so now he tries to preserve what he has. “There comes a point where you want to use a power chair to save your shoulders.” But not just any power chair works with his lifestyle. He needed a chair with all-terrain capabilities, so he ordered an OmegaTrac by Teftec.

His admittedly hopeful plan was that his insurance company, Blue Cross, which up to that point had provided excellent service, would be able to see his unique need. To make certain they understood, he engaged an occupational therapist to do an exhaustive, 20-page summary/analysis of his ADLs and rural lifestyle. Nice try, but didn't work.

“They should be deciding these cases on a case-by-case basis, but they were unwilling to negotiate,” he says. He feels that Medicare policy, specifically the outdated “in-the-home” restriction, is responsible for his insurance company's denial. “Insurance companies are falling back on Medicare policy and using the “in-the-home” language to their benefit in order to deny equipment and save money.”

What galls Reynolds most is that in rehab he was taught to do as much as he can possibly do, and now his insurance company, following CMS' lead, is doing its best to restrict his lifestyle choices.

While lifestyle restrictions imposed by insurance companies may be understandable to some, how can restrictions placed on our health needs be justifiable? James Parsons, 27, a T6 para for five years

took time off from his job in Portland, Ore., to travel to Detroit for a three-week intensive rehab program at the Rehab Institute of Michigan last year. He wanted to maximize the potential of his core muscles and stay in shape for future breakthroughs in SCI restorative therapies.

His father, Roger, had met with Dr. Wise Young in China while researching olfactory ensheathing cells treatment options, and Young had told him the best piece of equipment that James could buy would be a stander, to keep his bones strong, among other health benefits. James ordered an EZ Stand Evolv Glider because it combined exercise with standing and stretching, fully expecting that his insurance company, United Health Care, would see the health benefits and cover the cost. They even knew of someone else who had succeeded in getting UHC to cover this model.

But UHC denied Parson's initial claim, which set in motion a campaign of letter writing between a very determined father and son and an extremely unresponsive insurance company. The Parsons have been careful to document everything in their seemingly endless appeals process, beginning with an internal appeal, which was denied, and moving on to a second appeal, which was also denied, and, finally, to an external appeal, just denied in April. During this process the Parsons have sent untold numbers of letters and have provided documentation of the benefits of the stander for James' particular condition based on applicable clinical trials, but UHC, playing the role of institutional ostrich with head-in-sand, stubbornly refuses to acknowledge those benefits.

The irony of all this is that UHC paid for James' intensive three-week therapy at RIM, where he used the exact same model of stander and where he obtained letters of support from physical therapists who worked with him. Still, UHC would not approve the same stander for use in his home.

Not only does the insurance company's position not make logical sense, but it does not make monetary sense. UHC was willing to pay \$5,000 or more for three weeks at RIM but they refuse to pay for a stander/exerciser that the Parsons would be able to make effective use of for years. And what are the benefits of this particular model of stander? Strong bones, enhanced circulation, improved urinary tract and bowel function, less chance of pressure sores, even some cardiovascular benefit.

Apparently, even though the principle of preventative medical care is universally praised, cost-effective treatment is not high on the list of some insurance companies. The Parsons fully intend to seek help from their state legislators.

As unresponsive as Medicare and insurance companies are, there are other potential flies in the ointment. Janet Nordgren, 34, feels that most of the problems with getting a new TiLite wheelchair can be traced to an equipment dealer that was less than competent. To be fair, part of the blame is

(Continued on Page Five)

EQUIPMENT, CONT'D

Nordgren's, and part is due to the nightmare of paperwork that dealers face in getting the right equipment in the first place. Nordgren's history of wheelchair purchases is a lesson in itself. When she sustained an SCI at the T12 level at the age of 22, her first chair was a Quickie, which served her well, but she opted for a TiLite replacement several years later. Although she lives in Massachussettes, a physical therapist at Craig Hospital in Denver helped with ordering her chair, and to date, this is the best experience Nordgren has had in purchasing equipment. "They were awesome, they knew exactly what to do."

When it came time to replace the TiLite, she called someone she knew at TiLite who helped her fill out all the measurements and specifics over the phone. When her chair arrived, she realized she had made a mistake in ordering. The chair wasn't right for her. So this time she went to her local DME dealer to re-order. The same thing happened again. On the third try, the order went through without problems, but the protracted three-part process, mired in paperwork and delays, took 1.5 years to run its course. And she ended up having to pay significantly more than the insurance company allowed.

"I am very fortunate that I have a good job and I am able to get what I need," she says. "I can't even imagine what it is like to have to deal with all this without the right support or enough money to get the right equipment. Maybe it was just this particular situation, but the people I dealt with did not know what they were doing, and this complicated the process."

Getting the chair you need is more complicated than ever today. Medicare and insurance companies are restructuring the process and narrowing windows of approval. Longer delays are the norm. DME dealers are squeezed by lower reimbursement allowables and more complex and time-consuming documentation.

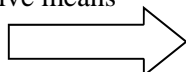
THE "SUPERSTAND" WHEELCHAIR

On June 18, 2008, the Center for Accessible Living provided a training for its staff on one of the newest wheelchairs entitled the "Superstand" Wheelchair. The wheelchair was demonstrated by a representative of The Standing Company.

The inventor of the "Superstand" has been a wheelchair user for 22 years. He incorporated many safety and comfort features into the chair, including a design that makes transfers easier. The chair, which can safely hold the weight of up to 400 lbs, weighs 160 pounds and is designed so that the stander will not fall over if the wheelchair is bumped. It comes in manual or power, and is custom-designed to meet the individual needs of the user.

The cost of a manual chair starts at \$9,200. The Standing Company will actively pursue creative means

CONTINUED UNDER FOR SALE



FOR SALE ***

WC Lift; \$1,700; Invacare Storm TDX 3 Power WC; full reclining; less than 1 year old; \$1500; Call David 589-6620.

NC topper; used; 3 E&J Manual chairs; used; 1 Quicksilver Action manual chair; Monarch hand controls. 93,000 miles. Price negotiable. Call Ruth @ 239-9754 after 5 p.m.

***Shower Chair; 2 yrs old, negotiable; Invacare 900 Action Power Chair; 4 yrs. Old; \$600. Call 448-5296.**

***Cookbooks for Sale: Recipes compiled by Chapter members; \$10:00. Call David @ 589-6620.**

***Video tapes for sale. Various topics related to spinal cord injuries. Call David Allgood or Buddy Lawson.**

****If assistance is needed to pay for any of the above items, contact Kentucky Assistive Technology Loan Corporation at 1-800-327-5287 for information on loans at 5% interest to qualified individuals.*

Our shirts are for sale, too!

S, M, L XL
\$10



"SUPERSTAND", CONT'D

of funding. Some sources include Medicaid/Medicare, private insurance, Vocational Rehabilitation, MS Society, Brain Injury Association and Veterans Administration.

Standing reduces the occurrence of bladder infections and pressure sores. Other benefits include:

- ◆ Improved circulation
- ◆ Lessening of spasticity
- ◆ Stretches hamstring and heel cords
- ◆ Helps prevent calcium loss in bones
- ◆ Reduces the occurrence of kidney stones
- ◆ Helps to keep lungs clear
- ◆ Reduces swelling in lower extremities
- ◆ Lessens the risk of knee contractures
- ◆ Strengthens the cardiovascular system
- ◆ Improves orthostatic circulatory regulation.

For more information on the "Superstand" Chair, call 1-800-782-6346 or visit www.thestandingcompany.com



HAPPY 4TH OF JULY!!!!

You are cordially invited to join us!

The Derby City Chapter of the National Spinal Cord Injury Association consists of people with spinal cord injuries and similar physical conditions, their family members, friends, and professionals or other interested parties.

We meet:

WHEN- Third Monday of every month from 6:30 to 9:00 PM

*WHERE- Frazier Rehab Institute, 10th floor Dining Room
220 Abraham Flexner Way, Louisville, KY 40202*

If you wish to be a member, donor, and/or be on the mailing list of the Derby City Chapter of the National Spinal Cord Injury Association please complete and mail the following form to the address below

National Spinal Cord Injury Association

Derby City Chapter

Membership & Organization Sponsorship Form

Name: Mr./Mrs./Ms./Dr. _____ Date _____
 Address: _____ Apt.# _____
 City/State/Zip: _____
 Business (if any): _____
 Home Phone: () _____ Work Phone: () _____
 Date of Birth _____
 Para: _____ Quad _____ Hemiplegic: _____
 Level of Disability _____ Other Disability _____
 Able-Bodied(yes/no): _____
 New Member: _____ Renewal _____ Newsletter Subscription
 (only \$12): _____

Special Interests /Hobbies/Sports: _____

Membership is open to all individuals and sponsorship to all organizations interested in spinal cord injury.

Mark Type of TAX DEDUCTIBLE Individual Membership or Organization Donor Category Desired***

- | | |
|------------------------------------|--|
| _____ Regular-\$12 | _____ Bronze Organization-\$100-249 |
| _____ Sponsor-\$25 | _____ Silver Organization-\$250-499 |
| _____ Patron \$50 | _____ Gold Organization- \$500-999 |
| _____ Benefactor-\$100 | _____ Platinum Organization-\$1000-2499 |
| _____ Permanent- \$1000/lifetime** | _____ Diamond Organization-\$2500 Or Over. |

Please make checks payable to: **NSCIA Derby City Chapter**

David Allgood
6703 Triangle Drive
Louisville, KY. 40214