

IVUN News

Assistance Dogs for Children with CCHS

Linda Thompson

As my husband and I looked around at the many growing children at the CCHS conference in Tennessee in 1998, we also looked at our daughter Heather (now 17) and asked the question, "What next?" Where would she be in the years to come? What kind of support would she need? What would be her options as she began to think about college and life beyond? What would happen to her nursing care in college, knowing that even now nurses sometimes simply do not show up? Would the college step in to provide a safe environment for her? Thus, we began to think and to explore outside the box.

In Heather's case, once she is awake she can handle any problems she has with her equipment, from disconnects to tubing changes, so we came up with the idea of an assistance dog that could be trained to awaken her to the LP10 ventilator alarms. The first time we broached this idea to Heather's physicians they were less than enthusiastic, but not completely opposed. The next time we brought it up we had quite an exploratory discussion with them.

Encouraged, we went home and in the early months of 2000 began searching the Internet for assistance dog organizations. We also talked with all the assistance dog owners we encountered in the Maryland/Washington, DC, area. Heather sent out two dozen letters to

training facilities on the east coast, explaining her situation and why an assistance dog was important to her quality of life and independent living. Only one organization, East Coast Assistance Dogs (ECAD) in Torrance, Connecticut, was willing to train a dog to respond to a ventilator alarm.

By July 2000, Heather had her dog. Earlier, we sent audiotapes of the ventilator with the disconnect alarm sounds, and then Heather spent two weeks in training with Cole, a black Labrador retriever, at home. The trainer worked one-on-one with Heather until she officially became certified with her dog for public access.

The cost of an assistance dog is not cheap and can amount to \$10,000. In our case, there is a total of 2½ years of training – 18 months for basic training, 6 months for specialized training for the ventilator. ECAD encourages people to do some fundraising for their dogs. They will also work with state Medicaid programs, and, if the state pays for the dog, they accept that as payment in full. They will also work with families on a reduced rate if there is no other way.

Maryland, our state, provides the model waiver program that pays for nursing care after our regular health insurance is exhausted each year. However, they have no provision for assistance dogs. We presented the obvious cost savings to them,

plus the fact that New York, among other states, pays for assistance dogs, but they still said, "No." Then we went to our state senator who understood the benefits to the state and who has initiated legislation for the state of Maryland to cover the cost of the dogs. It is too late to benefit us, but we hope it will benefit others in the future.



Cole is a great dog. Not only has he been waking to alarms, but in almost all instances he is responding faster than our nurses ever did. Heather tests Cole almost every night when she awakens for one reason or another. The ventilator disconnects sometimes at the trach and other times at the exhalation valve. She reports that even though Cole is sleeping when a disconnect at the trach occurs, Cole is up and moving towards her even before the alarms sound. When the disconnect occurs at the exhalation valve, he does not awaken until the alarms sound. There have been instances in which Heather

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Home Medical Equipment Company Profits: Dispelling the Myth

Joseph Lewarski, BS, RRT

For many years, the media and lay communities have pointed a finger at the health care industry with suggestions of over-billing, inflated charges, and significant profits. This line of thinking developed during an era (1960s through early 1980s) that did not include complicated business barriers such as Medicare DRGs and prospective payment systems, managed care, and rapid (and expensive) technological medical advances. During this same period, consumers came to appreciate the benefits of employer-paid health insurance, Medicare Part A & B programs, and a growing Medicaid system. Health care evolved into a series of "entitlement" or "entitlement-like" programs, with everyone demanding only the best.

However, the health care industry is a *business*, although to say this in public often evokes cries of horror. Regardless of one's opinion or position, health care companies require a positive cash flow stream and net profits. *Without profit, the business will fail.* This explains why hospitals are closing or merging with larger systems. This explains why there are fewer corner drug stores, and "mom and pop" health care businesses are disappearing.

If you follow some of the publicly traded home care companies, you will have observed recent years of record financial losses, bankruptcies, removals from the public trade listings, major reorganizations, consolidations, and closings.

Despite these facts, most media and consumers perpetuate the

myth that *all* health care providers, especially home medical equipment (HME) providers, reap huge profits. I believe two key misconceptions fuel this myth.

First, there is the assumption that health care providers actually control the prices they charge for goods and services. **False.** Over the last 10 years, HME providers have faced declining payments for the products and services they provide. The *Balanced Budget Act of 1997* was one of the most severe, reducing home oxygen payments by over 30%. Medicare and most Medicaid programs employ a fee-for-service payment system for HME. Each item is assigned a code that is associated with a price schedule determined by Medicare or Medicaid. *They set the price, not the HME provider.* The price is referred to as the "allowed amount."

Under Medicare Part B, Medicare agrees to pay 80% of the "allowed amount" for a medically necessary HME item (which is determined by the insurance plan based on their internal policy and procedures). Most private insurance companies have followed this example and negotiate similar rates and policy for HME goods and services. In some cases, large insurance companies, able to leverage because of their size, have set pricing so low that many HME providers cannot service their clients. This is because the proposed payments are *at or below the provider's cost of goods.*

Second, there is the assumption that providers of health care goods and services, including

physicians, hospitals, home medical equipment dealers, etc., are in the same sector of the business as that of the insurance and pharmaceutical industries (and therefore have similar profits). **False.** We are customers, too. Health care providers have little influence over drug prices and insurance contracting. Too often, the ball is in their court; insurance companies own lives and drug companies own patents. This power and economy of scale often gives them the ability to dictate price and policy. This is in complete contrast to the HME providers.

At the last annual conference of respiratory therapists, I presented a lecture on activity-based accounting for the HME provider. I discussed the total costs associated with the delivery of HME products and services and compared those to the standard payments received from the different insurance systems, including Medicare and Medicaid.

In determining total cost, one must account for the HME provider's cost of the product, as well as the cost of warehousing, shipping/delivery, billing, 24-hour service, general overhead, and the cost of money while waiting to be paid (it is not uncommon for HME providers to wait as long as 4-6 months to receive payment).

I provided numerous "real life" examples of insurance payments for HME products and services that are equal to or below the typical HME provider's cost, such as home mechanical venti-

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A Petition to President George W. Bush and Congress ...

in support of David Jayne and the National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Chronic Illness

Dear President Bush and Respected Members of Congress:

My name is David Jayne. I am 39 and have had a 13-year battle with Lou Gehrig's disease, otherwise known as amyotrophic lateral sclerosis (ALS), a degenerative condition that causes my muscles to atrophy. I live in the community of Rex, 15 miles south of downtown Atlanta, Georgia. In early 1998, I had a tracheostomy tube inserted in my throat and was hooked to a portable ventilator. I use a computerized speech processor to speak. I receive my nutrition via a tube permanently inserted in my stomach. My mobility is limited to the ability to twitch three fingers. These medical conditions create an ongoing need for skilled nursing.

Admittedly, the disease I face is brutal and harsh, but I do not face this disease alone. I love my life, church, friends, community, and family. The adoption of the Americans with Disabilities Act (ADA), which your father so heroically signed into law, has opened many doors once thought permanently closed to people with disabilities. Along with the ADA, modern portable ventilators have created even more unparalleled opportunities for me to be an active and contributing part of my community.

Today, however, it is not ALS that stands in my way; it is a harsh Medicare policy. Under Medicare rules, a person is considered homebound when "leaving home is a major effort" and "When you leave home, it must be infrequent, for a short time, or to get medical care."

My Medicare home health care provider had been sending an attendant to my home for two hours a day, seven days a week since 1997 to help me get out of bed and take a shower. Last year my provider tried to terminate my service after I went to the funeral of a friend who had died from ALS. I skirted that challenge but it points to the harsh impact of Medicare's homebound rule.

Recently, however, because I gave inspirational speeches at my church and to a class of physical therapy students, participated in an ALS "fun run," and traveled with a college friend on an overnight trip to watch a football game, my Medicare home health care benefits were cut off. The provider was following a Medicare policy that no longer considers me "homebound" and thus eligible for these vital medical benefits. My Medicare benefits have since been restored, but at the cost of my freedom. I must now remain confined to my home to maintain these benefits.

I ask you now to change this harsh governmental policy which virtually has made me a prisoner in my home. I have learned of other people in similar situations with significant chronic illness. I value these Americans. I care about the quality of their lives.

I ask that we amend this policy. If individuals with significant chronic illness are able to acquire the technological and personal resources necessary to leave the home, they should be granted the freedom to do so and still receive the medical and personal care they need and deserve. If

a fair policy cannot be achieved due to financial constraints, let us work positively and creatively for better solutions.

Sincerely, David Jayne

The National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Chronic Illness

To read the mission statement of the National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Chronic Illness, go to www.amendhomeboundpolicy.homestead.com.

IVUN News readers are urged to sign the petition online.



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Respiratory Study with SCI Ventilator Users

Millennium Man Bill Miller

In early January I received a phone call from Dr. Danny Martin at the University of Florida. He told me about a small research grant he had received to test his theory that inspiratory muscle training can improve air intake and management for spinal cord injured ventilator users. The primary goals would be to increase ventilator-free breathing time and to improve speech ability. Participation would require three trips to the University of Florida in Gainesville. The first two trips would be for evaluation and testing of my initial abilities, and then a physical therapist would come to my home five days a week for six weeks to train my breathing muscles. They would come to me for free? Unbelievable! I agreed immediately.

Our first trip to UF filled a Friday afternoon with preliminary paperwork, testing, and a physical assessment. My parents and I met with all the people involved in the respiratory research (several students, therapists, and about six doctors with various specialties). The sharing of thoughts and conjectures was very candid, and I found it most enlightening and enjoyable. The doctors have the formal knowledge while my parents and I have the experiential, and we seemed to validate each other's ideas.

Our second trip was for the breathing endurance test. To pass the time and to make the breathing environment as "normal" as possible, Dr. Martin suggested I bring a movie to watch. On the way out the door, we grabbed two movies. The thought of needing two

movies to watch never crossed my mind; we were taking both to decide on one later.

For the endurance test, I was hooked up to several monitors (EKG, oxygen and carbon dioxide levels, heart rate, and tidal volume) and asked to breathe on my own without the ventilator for as long as I could. This consisted of me breathing in and out through my open trach tube as the physicians monitored the numbers. Every 15 minutes Dr. Martin asked me to rate my comfort level from 0 to 10 – 0 representing easy breathing and 10 being a struggle for air.

After the first 15 minutes, I rated my comfort level at 1. After the second 15 minutes, I indicated 2. I had absolutely no idea how long I would last during the endurance test. My record of ventilator-free breathing time was three hours, and I had only done that once – well over a year before. But watching the movie helped me to relax, the time rolled by, and every 15 minutes I indicated a comfort level of 2. The movie ended, and I was still going strong, so we started watching the second movie.

This breathing test was designed to last a maximum of three hours, but I went for three hours and 15 minutes. (Dr. Martin said that they let me continue for another 15 minutes so I could set a new personal record.) My numbers held up well, and my comfort level remained at 2. Now I get to "work out" my breathing muscles five days a week for the next six weeks. Then I must return to Gainesville and top this performance

The pilot project "The effect of inspiratory muscle strength training on mechanical ventilator-dependent spinal cord injury (SCI) patients" began in January 2001 and was funded by the State of Florida's Brain and Spinal Cord Injury Rehabilitation Trust Fund through the Brain Institute at the University of Florida. It is intended to provide enough data to evaluate feasibility, and, if the results are promising, to help secure funding for a larger project.

Our hypothesis is that people with SCI, levels C1-C6, who are ventilator users with some spontaneous breathing will increase inspiratory muscle strength through inspiratory muscle strength training, increase their spontaneous breathing periods, and enhance sound production.

Bill Miller is our first subject, and we hope to study six to eight subjects before moving to the next level. At this time, we are only studying subjects within a 75-minute drive of our Gainesville campus because the researchers are going to the subjects' homes, five times per week for six weeks. I expect to have preliminary data by July 2001.

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so that the research is deemed a success and a larger grant can be used to study more people. Next time we will bring three movies – I hope we will need them. ■

ADDRESS: Bill Miller (MaxNWM@aol.com; www.lookmomnohands.net).

Breaths of Life

Mark Horan

In 1968, at the age of 10, I was admitted to Children's Hospital in Washington, DC, for a spinal tap. The spinal tap revealed an ependymoma tumor at the C3 level that had been causing tremendous neck pain, often waking me up early in the morning and lasting until noon. My school-mates began to call me "stiff neck," because I held my shoulders, neck, and head immobile to reduce the pain.



The decision to operate to remove the tumor immediately was made. This type of spinal tumor surgery was still in its

experimental stages, and the tumor was only partially removed. During the procedure, my spinal cord was severed, leaving me a complete quadriplegic.

Twenty years later, I experienced a sudden inability to catch my breath. I went through six months of pulmonary tests at Stanford Medical Center and The Stanford Sleep Clinic to determine the cause of this sudden decline in my breathing ability. Finally, the medical staff conducted an MRI which revealed that the tumor had grown back, covering an area from C2 down to T4. It was now pressing against my phrenic nerve, impeding my breathing function and threatening my brain stem.

I was admitted to the hospital at once. That night I was given a nasal mask and hooked up to a ventilator. I could breathe again. The air felt so cool and good I

could actually taste it. The entire group of muscles that had slowly taken over the diaphragm's breathing function all relaxed in one great sigh of relief. I slept that night – the best sleep I had had in years.

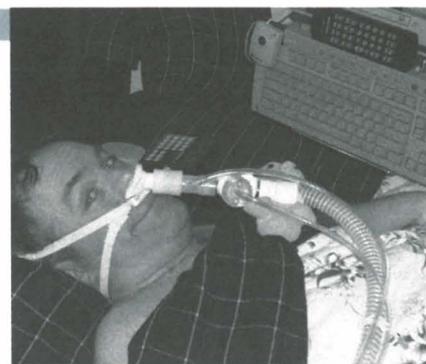
I declined further surgery because of low survival rates, but did agree to a six-week course of radiation concentrated at the top of the tumor.

One of the respiratory staff recommended that I use the ventilator only at night, as he believed (*Editor's note: erroneously*) that one's breathing muscles would become too dependent on the machine and atrophy somewhat. I agreed and did not use the ventilator during the day but struggled greatly to breathe during my daily routine. After several days of this, I decided to use the ventilator whenever I was lying down, day or night.

While sitting up, with the assistance of gravity, I am able to breathe without a ventilator, though it is labored breathing. The level of breathing difficulty is dependent upon many factors ranging from lack of sleep, a full stomach or bladder, air in my belly, the negative effects of consuming the slightest drink of alcohol, and even being too hot.

I remained in the hospital for a week to regain my strength and to learn how to breathe with positive pressure ventilation and nasal interface. I had been living on my own since 1976 and was discharged to my home with the PLV-100.

The first night home I spent several hours trying to get com-



fortable with the pre-formed, off-the-shelf masks I had used with some success during my hospital stay. After those who were helping me had exhausted their patience in trying to get the pre-formed masks to fit correctly without air leaking from the seal or without causing pain on the bridge of my nose, we all gave up in exasperation.

I phoned LIFECARE (now Respironics) the next day and was introduced to a customized SEFAM nasal mask formed from moldable putty, which would harden when a resin was added. It formed perfectly to my nose, and I have been using it ever since with no nasal sores or facial bruises.

The radiation I received to treat the top of this tumor seems to have abated its growth toward the brain stem, though not outward from my spine, nor has it stopped its downward march. However, the years of struggling to function have weakened my aging body somewhat, and I grow more dependent on the ventilator with every passing year, but, for now, no invasive means of ventilation are needed.

I am able to unhook the mask every morning while my attendants carry me into the shower, help me shower, and then return me to bed where I re-attach the mask. If I am going out, I can get dressed, unhook

CONTINUED ON BACK COVER

has not awakened after a disconnect until Cole has alerted her.

In talking with her physicians, there is an added alarm to which they would like Cole to respond: the oxygen saturation alarm. We are beginning the training on that, as well as training Cole to get help and to bring items to Heather. We are glad we have time to get Cole ready before Heather goes to college.

Challenges continue to be the acquisition of funding and the stabilization of nursing during Cole's ongoing training. Some of the nurses feel they are being replaced by Cole, but we try to explain that the dog is simply helping Heather to do more for herself and that, bright dog though he is, he does not have decision-making skills nor the ability to adjust ventilator settings. The medical director of the model waiver program is challenging the need for any nursing care in the home now that Cole is on

duty. We have explained that Cole is still in training and that he has not been certified in the eyes of Heather's medical team.

How has Cole affected Heather's life? Before Cole, she appeared outwardly, despite a trach tube, to be like other children. Having an assistance dog accompany Heather to school has changed that, with attention refocused on the fact that she is different.

At first, Heather was very nervous about the other children at school and how they would react. She appeared on a videotaped school announcement to explain about Cole and how the others were to interact with him. Now Heather reports that she has more friends than ever before, and people she does not even know will greet her and Cole in the halls. The teachers are now comfortable with Cole in the classroom and no longer notice that he is even there.

In public, Heather is sometimes challenged about bringing Cole into an establishment because she does not look like she needs an assistance dog. She is good at explaining that he is a working dog, but sometimes has to display her public access badge.

Cole is and must be Heather's complete responsibility. She feeds him, trains him, gets up early to take him out, cleans up after him, and plays with him. The rest of the family must refrain from any interaction with Cole until he is released by Heather. This intense bond is critical to the success of the program. Heather is the first to admit that Cole has changed her lifestyle, and she would not give him up for the world. ■

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Adapted with permission from *The CCHS Family Newsletter*, December 2000.

Home Medical Equipment Company CONTINUED FROM PAGE 2

lation services and nasal CPAP devices and masks.

In a review of the average HME provider's cost of goods and services, I provided evidence of insurance allowables for CPAP masks that were *lower than the provider's cost* of the product on nearly 80% of the masks available on the market. This analysis did not even take into account the cost of inventory, shipping, billing, etc. In addition, insurance companies often refuse to pay for more than one mask at the time of the set-up of the equipment and often allow for

only one to three replacements per year.

In reviewing the cost of providing home mechanical ventilation services, I presented examples of cases demonstrating that the HME provider was consistently providing home mechanical ventilation services at a loss, *once the total cost was calculated*.

The point of this article is not to seek sympathy for the HME provider, but rather to provide a more accurate picture of this complicated and important component of the health care industry. As we move forward into this new millennium, more health care will be delivered in

the patient's home or other non-traditional sites, and it is important for consumers to know the issues they and their health care providers are facing. I strongly believe that most HME providers are trying their best to provide the best care and service possible in the face of many complex obstacles. However, there is a cost in being the best and this cost is covered through the profits earned on the goods and services we provide. ■

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Potpourri

Greeley Center for Independence Wins Housing Grant for Ventilator Users.

A grant of \$12,500 from the Christopher Reeve Paralysis Foundation has been received by the Greeley Center for Independence to expand Camelot II, an apartment complex for ventilator users. Opened in 1986 with funds from HUD, the apartments offer an independent living arrangement with 24-hour attendant and/or nursing care. Camelot II is adjacent to the University of Northern Colorado campus. For more information on the program, contact Rob Rabe, MA, CRC, Greeley Center for Independence, Inc., 2780 28th Avenue, Greeley, CO (Colorado) 80631-7803 (970-339-2444, 970-339-0033 fax).

The Department of Health and Human Services (HHS) announced the release of nearly \$70 million in grants to states (by September 2001) to increase services and supports to people with disabilities, and to further implement the Americans with Disabilities Act. The funds include: \$50 million in "Real Choice Systems Change" grants to help states improve supports for people with disabilities to live in their own homes rather than be institutionalized; \$15 million in "Access Housing" grants and Section 8 housing vouchers to assist in the transition of people with disabilities from institutional to community-integrated living; and \$8 million for "Community-Based Personal Assistance Services" grants to offer individuals with disabilities maximum control. For the full text, see www.hcfa.gov.

Long-Term Mechanical Ventilation, edited by Nicholas S. Hill, MD, is an excellent new volume in the series *Lung Biology in Health and Disease*, published by Marcel Dekker, Inc. Written by the experts in this field, a partial listing of the chapters includes the epidemiology of long-term ventilatory assistance; effects of ventilation on respiratory muscle function; what happens in chronic respiratory failure; sleep-disordered breathing and nocturnal ventilation; use of long-term ventilation in restrictive disorders, use in people with severe COPD, and use with infants and children; management and monitoring of both invasive and noninvasive ventilation; conversion from invasive to noninvasive; and cost and reimbursement issues. Each chapter has an extensive bibliography. The book is very comprehensive and, despite the fairly steep cost of \$195, would be of the utmost usefulness to any pulmonologist or respiratory therapist wanting to learn all there is about this subject. Contact Marcel Dekker (800-228-1160; www.dekker.com). ■

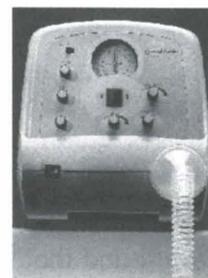
Calendar 2001

APRIL 5-7. Focus on Respiratory Care Conference, Cleveland, Ohio. Contact Bob Miglino, RRT, MPS (800-661-5690, BobM@foocus.com, www.foocus.com).

MAY 2-3. Beyond Ventilation: A Meeting of the Minds. Toronto Congress Centre, Toronto, Canada. Contact Marg Wagner, Citizens for Independence in Living and Breathing, 55 Greenwood Court, Kitchener, Ontario N2N 3H6, Canada (519-570-9713 phone & fax, cilb@idirect.com).

Equipment News

◆ **CoughAssist™**, the latest version of the In-Exsufflator Cough Machine (a.k.a. Cofflator), is now available from J. H. Emerson Co. It features a sleek new design, quieter operation, an adjustable, internal, inhale-flow restrictor, a simpler breathing circuit, and an optional mobile stand.



The noninvasive CoughAssist™ safely and effectively clears secretions, avoiding the need for suctioning while reducing the risk of respiratory complications. The CoughAssist™ can be used with a face mask, mouthpiece, or with an adapter to an endotracheal or tracheostomy tube.

It meets all USA, Canadian, and European electrical standards and is available in both an automatic and manual version. Contact J.H. Emerson Co., 22 Cottage Park Avenue, Cambridge, MA (Massachusetts) 02140 (800-252-1414, 617-868-0841 fax, www.jhemerson.com).

◆ **Mallinckrodt, Inc.**, which was sold to Tyco International in June 2000, announced that it is returning to the **Puritan Bennett** name for their alternate care home ventilation products. Formerly based near Minneapolis, the unit will be known as Puritan Bennett, a Tyco Healthcare Company, and is located in Pleasanton, California (800-635-5267).

The website is still www.mallinckrodt.com.

the mask, get into my power wheelchair, and go wherever I want for several hours ventilator-free. Though tiring, the relative freedom I experience is exhilarating. Upon returning, after 30 minutes lying down with the ventilator pumping fresh, cool air deep into my lungs, I feel like a new man.

I have found that being a ventilator user, though restrictive, is not prohibitive to a healthy, "normal," worthwhile, productive, and fulfilling life, but I could never have survived without the help of inventive friends and family. ■

ADDRESS: Mark Horan (MHoran5405@aol.com).

CAMPS FOR VENTILATOR-ASSISTED CHILDREN

JUNE 2-8. Trail's Edge Camp, Mayville, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 East Hospital Drive, F3064, Box 0208, Ann Arbor, MI (Michigan) 48109 (734-763-2420, mdekeon@med.umich.edu).

JUNE 11-16. Pennsylvania Vent Camp, Camp Victory, Millville, Pennsylvania. Contact Debra Randler or Michael Dettorre, DO, Pennsylvania Vent Camp, P.O. Box 850, Hershey, PA (Pennsylvania) 17033-0850 (877-455-3311, 717-531-0809 fax, drandler@psu.edu, www.collmed.psu.edu/pedsvent).

JUNE 16-22. CHAMP Camp, Recreation Unlimited, Ashley, Ohio. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis, IN (Indiana) 46240 (317-415-5530; 317-415-5595 fax, admin@champcamp.org, www.champcamp.org).

JULY 1-6. Camp Inspiration, Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 1056 East 19th Avenue, Denver, CO (Colorado) 80218 (303-837-2502, leidholm.monte@tchden.org).

AUGUST 2-5. CHAMP Camp Adolescent Retreat. For ages 14-18. Timberpointe Outdoor Center, Hudson, Illinois. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis, IN (Indiana) 46240 (317-415-5530, 317-415-5595 fax, admin@champcamp.org, www.champcamp.org).

AUGUST 31-SEPTEMBER 3. SKIP Camp, Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 118 Ned Avenue, Slidell, LA (Louisiana) 70460 (504-649-0882).

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