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the agency’s staffing levels. Diabetics, particularly complex diabetics, were the most affected by changes in admission practices that restricted or reduced levels of care.

- Chronically ill Medicare beneficiaries are among those experiencing greater fragmentation and disruption of care.
- The number of Medicare beneficiaries that the agencies in the study treated dropped 30% from 1996 to 1998, raising concerns both for access to care and its quality and effectiveness.
- A further 15% reduction in Medicare payments to home care agencies that is scheduled to take effect October 1,

2000, would further exacerbate these problems, putting beneficiaries’ health at even greater risk.

“As the researchers noted, Medicare home care beneficiaries generally are sicker, older, and poorer than Medicare beneficiaries in general,” says Val J. Halamandaris, president of the National Association for Home Care (NAHC). “Yet the Interim Payment System is designed in such a way that it makes it financially impossible for agencies to provide an adequate level of care to those frail patients who need care the most.”

Previous research cited in the GWU study has demonstrated the important role that home care has played in improving the overall health of homebound

patients. A study by the Institute for Health Care Research and Policy at Georgetown University found that patients with greater use of home care services were more likely to experience health improvements than similar patients with low home care utilization.

Home care providers from across the nation converged on Capitol Hill on September 15 to advocate for adequate funding for the Medicare home health program. The home care advocacy day was sponsored by five national home care trade associations, including NAHC, in an effort to convince members of Congress that the Medicare home care benefit must be preserved. (NAHC) ■

Home Care Coalition Steps Up Efforts

The AARC is working on numerous fronts to ensure appropriate reimbursement for home respiratory care and adequate access to these services for the patients who need them. Part of that effort comes in the form of the Association’s membership in the Home Care Coalition, a nationwide group made up of a diverse group of organizations representing consumers, patients, family caregivers, health care professionals, providers, and manufacturers dedicated to serving people in their homes. The Coalition’s primary mission is to enhance consumer access to quality home care services, supplies, and equipment. It accomplishes that mission through education and communications advocating the benefits of home care to policy makers and the public.

The following is the Coalition’s agenda for this year:

Home Care Coalition 1999 Issues

Promote the integrity and availability of the Medicare program and home care benefits

- Support further reform to the IPS (interim payment system) for home health agencies.
- Help shape the PPS (prospective payment system) for home health agencies.
 - Support adequate case mix adjuster
 - Eliminate 15% cut scheduled for October 1, 2000
 - Support outlier provision for high cost/medically complex patients

- Work with members of Congress on Medicare restructuring efforts, including:

- National Bipartisan Commission on the Future of Medicare report
- Part B drug benefit
- Medicare +Choice

- Oppose competitive bidding.

- Support the implementation of the regulation offering consumer choice in medical equipment upgrades
- Expand access to home care through HCFA’s home care coverage decision-making policies (e.g., definition of homebound, outlier/exemption policies)
- Oppose HCFA’s refusal to cover preventive services (legislative)
- Oppose the arbitrary cap on payments for outpatient therapy (PT/OT) services
- Work with the Medicare Payment Advisory Committee (expansion – support one candidate, reports)

Hold HCFA and its contractors to the same standards of professional, ethical, and legal conduct and accountability they expect from home care providers

- Oppose abusive HCFA actions.
 - Oppose violations of rules regarding the promulgation of regulations (IR, competitive bidding, surety bonds)
 - Hold HCFA accountable for

their inability to enforce current fraud and abuse safeguards

- Support due process protection for providers
- Separate the implementation of medical policy and fraud and abuse enforcements
- Oppose abusive carrier actions.
 - Oppose national and regional restrictive definitions of “homebound”
 - Monitor the burdens associated with the implementation of OASIS-ORYX
- Identify and address Y2K problems and excuses (payments, upgrade provision, competitive bidding, etc.).
- Oppose increased fraud and abuse measures that amount to unfunded mandates on the states.

Promote home care broadly

- Oppose overly restrictive definitions of homebound.
- Promote access to home care in managed care reform (e.g., Patient’s Bill of Rights).
- Support President’s Long Term Care proposal.
- Republish “Home Care: It’s the Answer.”
- *Promote/participate in appropriate efforts to reduce fraud and abuse in home care*
 - Oppose home health agency consolidated billing (bundling).
 - Support state licensure for home medical equipment companies.
 - Oppose overly restrictive surety bond requirements. ■

MedTrade Show Creates Scheduling Conflict in 2000

Many of you are probably aware of the date conflict Health Care Group created when they scheduled next year's MedTrade show for early October immediately prior to AARC's 46th International Respiratory Congress. We share your

concern over this problem recognizing the financial burden it will create for our members who want to attend both shows as well as the difficulties it will cause for our regular exhibitors who also attend the MedTrade show. We regret the hardships this sched-

uling problem may cause for you and our exhibitors at our meeting next year in Cincinnati. To help prevent such obstacles with future AARC meetings, Sam Giordano sent the following letter to Health Care Group's Joe Randall.

November 8, 1999

Joe Randall
Group Director, Health Care Group
Bill Communication
P.O. Box 17413
Washington, DC 20041

Dear Mr. Randall,

I want to take this opportunity to express my disappointment regarding your scheduling of next year's MedTrade show. I've recently learned that MedTrade is scheduled to convene on October 3rd and end on October 5th. As you may be aware, the American Association for Respiratory Care has scheduled its 46th International Congress to convene on October 7 and end on October 11. Since several of our attendees and exhibitors are also your attendees and exhibitors, your scheduling of MedTrade immediately prior to our Congress will pose a hardship for these individuals and companies. AARC's 46th Congress has been scheduled for several years. We have announced the dates frequently in the intervening years. I hope that in the future, when Bill Communication is considering dates for MedTrade meetings, you will consider the potential for conflict with the AARC Congress. We have and will continue to check MedTrade show dates prior to committing to specific dates for AARC's future shows. I would ask that Bill Communication provide the same consideration in order to optimize exhibitor support and attendance for both meetings. AARC's future show dates beyond next year are:

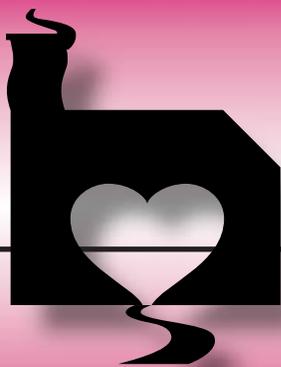
2002 — Tampa, FL, Oct. 5-8
2003 — Las Vegas, Dec 8-11
2004 — New Orleans, Dec 4-7

Thank you for your consideration.

Sincerely,

Sam P. Giordano, MBA, RRT
Executive Director

SG/bd



Home Care

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Notes from the Chair

by Joseph S. Lewarski, RRT

Greetings! As we near the end of 1999 it seems as though there is still so much we have yet to accomplish. My first year as section chair has been interesting and sometimes challenging. I've enjoyed meeting many of you at the different shows and hearing from you via e-mail and telephone. I look forward to 2000 and my second year as chair. I'll continue to do my best to meet my primary goal of assuring that all AARC personnel, as well as all the other health care providers I meet, learn and appreciate the value and importance of the home care respiratory therapist.

The key articles in this issue are from a pediatric ventilator-dependent patient, his mother, and the respiratory therapist who follows him in the home. As I mature in my role as a home care clinician and executive, I have gained a greater appreciation for the patients and families who receive our services. Thanks in part to improving technology and greater recognition of home respiratory service, many patients with chronic illnesses can enjoy the quality of life they desire and deserve. Much of the credit,

however, needs to go to the "real" caregivers who do the bulk of the work. This includes the parents, sons, daughters, grandparents, foster parents, etc., who live in the homes of our patients and provide the 24 hour per day, 7 day per week care.

Indeed, it is sometimes too easy to overlook the patient's perspective. Reduced insurance payments, managed care hassles, FDA, OSHA, JCAHO, etc., often become such big hurdles in our daily jobs that we are distracted from the true focus of our business — to provide medical equipment, supplies, and services to patients in the home. Technology-dependent patients in particular face and overcome obstacles daily that we sometimes fail to recognize.

Over the years I've learned (and continue to learn) the value of the patient's perspective. They often prove me wrong when I have formed my own preconceived notions about prognosis, dedication to care, and outcome. With each experience I try to learn and form a new and greater respect for the patients and families we have the privilege to serve.

Please enjoy the articles in this issue. ■

Consensus Conference on Oxygen Therapy

Dr. Thomas Petty recently led an invitation-only consensus conference in Washington, DC to discuss issues and standards of care for the provision of long-term oxygen therapy. This conference was held in September following the AARC-sponsored scientific conference on oxygen therapy, which took place in August in Cancun, Mexico. Key clinical leaders, home care company clinicians, manufacturers, and patients from around the country met to review the current research, technology, and reimbursement issues.

The goal of the conference was to formulate a consensus statement regarding the provision of home oxygen therapy in today's health care and insurance environments. Featured speakers included Dr. Petty, Dr. David Pierson, Dr. Richard Casaburi, and Dr. Paul Selecky, among others. Special thanks go to Robert McCoy, RRT, BSM, and Peter Bliss of Valley Inspired Products for their efforts in organizing this conference. You can look for the published consensus statement in a future edition of *Respiratory Care*. ■

Four Perspectives

The following four articles provide a unique "window" on the world of a pediatric home care patient with spinal muscular atrophy. Kevin Anderson, his mother Carolyn, his physician, Carolyn Kerckmar,

MD, and home care RT Thomas Kallstrom, RRT, offer us all their own particular insights into what it means to be and to care for a technology-dependent 16-year-old. Their views on compassionate

care and quality of life serve as an eloquent reminder that there is more to respiratory home care than just the delivery of timely equipment and services. ■

An Adolescent's Point of View

by Kevin Anderson

Over the years, I have seen the good and bad aspects of respiratory health care and its professionals. Because of my disease, I have had encounters both at home and in the hospital. I am pleased to say that my recent experiences with home respiratory therapists have been very good. My current home respiratory therapist is the main reason for this. He is the first respiratory therapist who has consistently listened to my lungs, taken my pulse ox, asked me what needs to be improved, and shown significant respiratory knowledge. This may not sound like much. It should be the norm. However, many of my previous encounters with home respiratory therapists do not support such.

In many of my experiences, these home respiratory therapists seemed more concerned with the money and

reimbursement issues than the well-being of the patient. They were not functioning as the respiratory therapists they claimed to be; in my opinion they were salesmen. If they truly were knowledgeable respiratory therapists, why would they have to ask my nurse, my mother, or even myself how to set up my ventilator circuit? They would ask my mother if I had been sick recently or was on antibiotics, but they never actually listened to my lungs or did a clinical assessment. Over the years, I have had problems with the ventilator alarming for no apparent reason. I was made to feel that *I* was the problem, not the machine.

While my experiences with home respiratory therapists have been generally negative up until now, my hospital experiences with respiratory therapists have been more positive. Because I have been hospitalized my fair share of times, my family and I have become friends with some of them. I have very few complaints about the quality of care I received from respiratory therapists at the hospital. (I normally go to a prestigious pediatric hospital.) In fact, I can only remember having one problem with a hospital therapist.

I was hospitalized for two weeks with a bad pneumonia and was requiring continuous ventilation. Towards the end of my stay, the process of weaning me off the ventilator began. About this time, a therapist came into my room to discuss my current ventilation needs and weaning. Right off the bat, his tone was very negative. He said to me, "Now, there's a good chance that you may never come off the vent." Thanks for the comforting words! That statement really scared me. My mother was able to comfort me after he left. The point is that he should not have started the conversation by emphasizing my worst case scenario. With better communication skills, he could have mentioned it once, and told me that they were hopeful that I would be just fine and would work hard to wean me. By the way, I was off the ventilator within two weeks.

I don't think that I ask too much of my respiratory therapists. I'm sure that most have achieved a fairly high level of respiratory knowledge and know what they are doing. They should show legitimate concern for my well-being. Finally, I ask that they be honest with me without scaring me. ■

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A Parent's Point of View

by Carolyn Anderson

I've learned a great deal in the 16 years since Kevin, my son, was born with spinal muscular atrophy (SMA). New words, such as postural drainage, atelectasis, intubate/extubate, and tracheotomy somehow crept into our everyday vocabulary. Old, familiar words such as disability, quality of life, and even death would take on a whole new meaning. Mostly however, I've learned that miracles do happen and "miracle workers" are everywhere.

I can say, with some degree of certainty, that Kevin will never be a poster child for The Children's Miracle Network Telethon. Kevin still has spinal muscular atrophy. No medicine, treatment, or surgery has been able to erase that from his body. Today, he sits in a wheelchair,

breathes out of a tracheostomy tube, and receives supplemental nutrition through a gastrostomy button. He is a miracle, nonetheless, not for what he cannot do, *but for what he can do.*

Kevin may not be able to write legibly, yet gets straight A's in school. His tracheostomy tube may prevent him from talking loudly and clearly, yet he accepts the challenge of public speaking without complaint. Though Kevin cannot physically participate in the sports he loves, he has become an expert on them all.

I believe there are two different kinds of miracles. One happens through curing; the other happens through caring. The first relies on "the miracle worker;" the

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other relies on miracle workers disguised as doctors, nurses, therapists, family members, and friends. Both are extraordinary in their own right.

From early on, I realized that my family's survival in the real world would rely on daily doses of "optimistic realism." Optimistic realism is better understood by example than by definition. At four years of age, Kevin was in the PICU for the second time in two months with a serious respiratory infection. I was feeling pretty low, but the pediatrician reminded me he had come through it once before and not to give up on him. We both knew it could go either way, but he reminded me there are two sides to each coin. Kevin recovered completely.

Several years ago, Kevin was faced with another serious pneumonia. Though Kevin is normally on a ventilator only at night, this time he was on for 24 hours. One respiratory therapist repeatedly stressed to Kevin that there was a good

chance he would not be able to come off the vent. Within ten days of leaving the hospital, he was back to just nighttime ventilation. This therapist, obviously, possessed only one-sided coins.

I've come to realize the humanness of health care professionals, be they doctors, nurses, or therapists. I say this not out of bitterness, but out of a deep respect. I've come to realize no one person can be expected to know everything about every disorder. However, what I think families have every right to expect is that medical professionals listen to families with an open mind and a willingness to try new things.

When confronted with what I perceived as a worsening of my son's respiratory status, the pediatric pulmonologist called in a respiratory therapist "who'd been around for quite a while" to discuss different alternatives. He listened to what our needs and concerns were. *Together* we agreed on IPV treatments. It has since become a part of Kevin's daily routine.

Some time later, I approached the

same pulmonologist with information I had gotten at an SMA conference on the In-Exsufflator and how it seems to benefit some children with spinal muscular atrophy. She listened, read up on it, and ordered it on a trial basis. Unfortunately, one of the home care therapists was not quite as open-minded. He told us he would be surprised if we saw any change at all. We tried it, and we liked it. It has had a major impact, not only on Kevin's health, but also on the quality of his life.

Lastly, I have come to understand that the only way Kevin will thrive at home and in the community is if families and professionals establish a partnership. I believe we have that right now with Kevin's pediatric pulmonologist, home care respiratory therapists, and nurses. Sometimes they will teach, sometimes we will teach. Who teaches is not important. *What is important is that we both listen and learn from each other. Perhaps that is the real miracle.* ■

A Physician's Point of View

by Carolyn Kercsmar, MD, pediatric pulmonology, Rainbow Babies & Children's Hospital

Physicians often learn from their patients. The lessons arrive in the form of medical observations, physiologic measurements, or portraits of personal triumph. Providing medical care for Kevin has afforded me rich learning opportunities in all arenas.

The decision to recommend a tracheostomy for a patient is never made without enormous consideration and deliberation. Interposing a plastic detour in the airway of an intelligent and loquacious young man such as Kevin may bypass his pharynx, but not his soul and spirit. When a tracheostomy appeared to be the only path off the ventilator following a bout of pneumonia and chronic lobar atelectasis, no one was pleased with the decision. Angst and frustration from parents and physicians abounded: what could we have done to avoid this, how could we impair what was for him a major passion — talking to everyone and voicing his firm convictions and opinions about most everything, especially sports. Kevin, however, did not want to try breathing again without some help. The trach went in, and no one breathed easier.

Lesson one: always listen to the patient (particularly ones with lots to say). No cuffed trach tube, please. Talking is paramount, for safety, for

personal growth, for learning, and for telling the doctor exactly how you feel. There were numerous travels down the airway with the bronchoscope to hunt for the dreaded "rocky secretions" tormenting Kevin and requiring endless suctioning and hours on the ventilator. New pneumonia, bronchitis, medication trials, and learning to talk again were challenges as well. The hurdles were met and conquered with all the grace and spirit of an elite athlete. Complications lessened in the objective, and perhaps jaundiced, eye of the physician. But Kevin and his family had other thoughts. Specifically, did the trach need to become a permanent part of life?

Primum non nocere — first do no harm. It's the ultimate credo for physicians and sometimes the most haunting. The request to explore decannulation and non-invasive ventilation arrived as expected. Most of the research was initiated by the Andersons, and I followed their lead, albeit slowly.

Discovering that the tracheostomy could possibly come out in favor of non-invasive ventilation was a revelation at our center. What was the best option? Intrapulmonary percussive ventilation (IPV) and the enormous success it provided for Kevin in terms of reducing amount of suctioning, improving atelectasis, and

minimizing pulmonary exacerbations were impressive. Resurrecting an old therapy, the "cough-a-lator," complemented the IPV treatments beyond expectations. The combination of nocturnal ventilation, daily IPV, and use of the In-Exsufflator relegated frequent hospitalizations to the ancient history domain and led to the decision to keep the trach. And his voice was good as new, spewing forth more sports facts, opinions, and predictions. (Never mind the bad advice he gave me about Kansas in the Final Four one year!)

Adaptation, survival, and success prevailed because of a diligent family and a brilliant young man with more courage, dignity, and strength than any of the star athletes about whom Kevin knows everything. ■

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A Home Respiratory Therapist's Point of View

by *Thomas J. Kallstrom, RRT*

I have known Kevin Anderson from day one of his home care experience. I was fortunate to be one of the first respiratory therapists assigned to him during his first admission for a serious respiratory infection and compromise. This took place at Rainbow Babies and Children's Hospital in Cleveland in the mid 1980s. I also helped coordinated his discharge with his family, his pulmonary physician, Dr. Carolyn Kerscmar, and his first home care company. (Kevin has been with additional home care companies since his original discharge from the hospital.) He was one of the first patients to be discharged from Rainbow Babies and Children's on a home care ventilator. Today this practice is much more common.

Kevin has been fortunate because he is blessed with a devoted family, an exceptional physician, an affiliation with one of the world's best pediatric facilities, and most recently, an attentive home care company. For any home-going mechanically ventilated patient, most of these variables need to be in place if there is to be any measure of success.

It wasn't until a couple of years ago that I was able to again work with Kevin

in his own environment, his home. Any respiratory therapist or nurse who works in an acute care facility and functions at the level of caregiver, educator, or discharge coordinator with patients like Kevin should spend a degree of time in the patient's home. There is a world of difference between the two. Hospital-based clinicians who have never worked in a patient's home are only fooling themselves if they think they understand this difference.

Much can be learned by spending time at the patient's home. A mini-intensive care unit set up in a patient's dining room does not have the same accoutrements as one in a tertiary care center. In an emergency situation, a code cannot be called. It is up to the family and any available medical personnel to resolve the emergency. Because the customary resources that a hospital possesses are not available in the home, it is essential that family and caregivers are competent and demonstrate the required skills to care for a life-support system. The home care company also serves as a lifeline to the patient. If supplies are in short supply, there must be a fail-safe communication between the

home and home care company. Immediate response from the home care company should be the norm. In short, only the best and certainly most experienced staff should care for patients on these types of systems in their homes. All home care companies and clinicians are not equal.

Although I currently serve as a department director for an urban-based community hospital, I still work part-time in home care so that I won't lose touch with important patients like Kevin. My role with Kevin is to visit him monthly. During this visit I can answer questions, act as an intermediary to the home care company, verify that the patient is complying with the physician's order, and identify needed changes in the care plan and then to communicate them to the patient's physician.

There will be other Kevins in the future. As respiratory therapists, we need to be attentive to the needs of these patients. We also need to keep an open mind and be willing to accept that which we once did not. I have learned much from Kevin and his family, as I have with others. ■

AARC Asthma Disease Management Program is a Success!

Cleveland, OH was the place to be on September 24 and 25. The AARC's Disease Management of Asthma Program, sponsored by Sepracor, was an overwhelming success. Approximately

200 AARC members from all over the country attended two days of lectures on all aspects of asthma disease management. Thanks need to go to the AARC, Sepracor, and Thomas Kallstrom, RRT,

for organizing this program. Early reports from attendees suggest the lectures and speakers were outstanding. Look for this program over the next year in other parts of the United States. ■

Medicare Cuts to Home Health Hurting Access to Care

Medicare cutbacks for home care services, enacted under the Balanced Budget Act of 1997, are jeopardizing the health of the sickest, most vulnerable home care patients, according to a study released last fall by The George Washington University (GWU) Medical Center.

The study, "An Examination of Medicare Home Health Services: A Descriptive Study of the Effects of the Balanced Budget Act Interim Payment System on Access to and Quality of Care," looks at how care for Medicare beneficiaries receiving home health services has been impacted by cuts to the

Medicare home care program. The cuts were enacted in 1997 through a new payment method called the Interim Payment System (IPS).

Among other findings, the study concluded that:

- As many as half of the non-profit agencies in the study must subsidize care for Medicare patients by using funds from their endowments or direct contributions, indicating that for many patients Medicare payments do not cover the actual cost of providing care.
- Nearly all agencies in the study reported making significant reductions in

clinical and administrative staff in an effort to contain costs under the Medicare cuts. Skilled nursing staff has declined by 23% since 1994, leaving fewer home care professionals to meet the needs of a growing elderly population.

- Given these reduced payments and reduced capabilities to provide clinical care, home care agencies are being forced to closely analyze whether they can admit patients whose care will either be too costly or cannot be performed at

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