

Needed: Independent Living for Ashly

Donnalee Livingston, Rochester, New York, donnaleel@yahoo.com

In July 2004, my grandniece Ashly Gambino was shot at a residence in Raleigh, North Carolina. At that time, she was barely sixteen, and the bullet burned through her spinal cord at about C2-C3.



Ashly Gambino

Her journey thus far has been tedious. Her parents were unable to cope, and she was left with just a few extraneous family members to help her reach her goal of moving back to New York, finishing her high school education and living outside of an institution.

Her first institution was WakeMed Raleigh, where she was taken after she was found at a convenience store parking lot fighting for her life. The perpetrator had dragged her to a car from the residence at the owner's demand and called 911 from the store lot. WakeMed treated her as a trauma center does, and later put her in the geriatric ward because it appeared that she would live. They would search for long-term care for her.

In October, Ashly had movement in her limbs and, because of that development, the Shepherd Center in Atlanta entered her in their spinal cord program. The Center is full of young people striving to find ways to take care of their own lives, looking for independence, and realizing that there can be life after paralysis. She had so much fun there and became determined to live a full life. However, not the life she had previously dreamed.

The Center worked with Ashly but was concerned all the while about her lack of guardianship. She remained there from January through April 2005 when I was able to find a New York facility to take her, Medicaid pending.

Ashly did not have a New York Medicaid number yet because she was still covered under North Carolina Medicaid. The Northeast Center for Special Care, Lake Katrine, New York, had room for Ashly in their Ventilator Care and Ventilator Weaning Program, and freely accepted her as she awaited her transition into New York's Medicaid program. Ashly stayed there from April until July.

It was an absolutely frightening and disgusting existence for this teenager far away from home with no way to defend herself. She was often confined to her room, but she did have great therapists working with her to help strengthen her neck muscles and to gain more movement.

Finally in July her Medicaid number came through, and The Highlands at Brighton, Rochester, New York, accepted Ashly into their Long-term Ventilator Unit. There are only two places in Rochester that will take patients who use ventilators long term: The Highlands and Unity Living Center. Unity did not feel that they had the right facilities for Ashly.

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International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

Inside this Issue ...

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Needed: Independent Living for Ashly

Vent-assisted Ashly Gambino has a champion – her aunt Donnalee Livingston, who has tackled the health care system in the US. The latest barrier has both of them “reeling” and creative solutions are sought from IVUN Members.

Pages 4 and 5

Truly Personal Attendant Care

Long-time IVUN Member Peg Nosek sent a holiday greeting indicating her ventilator-assisted life is filled with joy. In this issue, she writes about her unique solution to attendant care that has evolved from her specific circumstances and opportunities. It may be an option for others.



Pages 6 and 7

Take Charge, Not Chances: In Practice

Post-Polio Health International and IVUN's board president takes his leadership role seriously. After reading Take Charge, Not Chances, Larry Becker methodically worked his way through the checklists and in this article offers advice.

Pages 8-10

From Around the Network

IVUN Information Specialist, Judith R. Fischer, alerts the Network of the latest equipment, acquisitions, resources and events. A blog called The Pandemic Ventilator Project is an interesting spot that discusses the possible shortage of ventilators during a major outbreak of any disease that would require assisted ventilation.

IVUN invites you to contact info@ventusers.org with networking information for future issues.

Gladys Swensrud, a bilevel device user, has selected her favorite mask and has written why for publication in the next issue of *Ventilator-Assisted Living*. Do have a favorite interface? If so, send your comments to info@ventusers.org.

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Remember the deadline for Phase 1 application for The Research Grant is March 3.

And, once again, we thank our sponsors and Members for their continued support.

—Joan L. Headley, Executive Director

Needed: Independent Living for Ashly

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It was a lateral move for Medicaid and they would not bear the expense, so we got together the \$2500 to move her to Rochester where at least we could visit her.

Since her move, I have been working with The Center for Disability Rights in Rochester to find housing and care for Ashly. There are other ventilator-assisted young people living on their own in Rochester, and Ashly was ecstatic to think that she could get out of the geriatric ward and live among younger people.

I have been working for more than two years trying to put all the pieces together. I meet stumbling block after stumbling block, yet all the while she encourages me. We have finally found appropriate housing for Ashly in Nunda, New York, in a newly constructed complex for people with lower incomes and seniors. The managers have gone out of their way to make one unit especially for Ashly. It has a roll-in shower, Hoyer lift ceiling track, generator, special flooring, etc.

The latest stumbling block has me reeling. Ashly could have moved into this apartment last November, but we

could not find an agency that would provide care for her.

She obviously needs 24/7 care, but it doesn't have to be private duty nursing alone. We could mix and match that care according to her daily needs. There are agencies that provide services in the area, but they are refusing to take her case because of the ventilator — she uses the LTV®950 (www.pulmonetic.com). Now Medicaid will not approve 24/7 nursing for Ashly to live alone in an apartment.

The apartment will not be held very long for her. Her goals to get to New York and to get her high school diploma have been met. Ashly wants to shop for her own food, make her own menus, eat when she is hungry, and not be at the mercy of caregivers who work by the clock and not always in her best interest. She wants what we all want: to be among people living ordinary lives, developing relationships, finding purpose and a reason to get out of bed in the morning.

Anyone with creative suggestions and solutions is welcome to contact me at donnaleel@yahoo.com. ▲

US progress in providing personal assistance services

The Centers for Medicare & Medicaid Services (CMS) requested public comment on *Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling)*. Recipients would retain control and authority over how the services are provided, who provides the services, the hours they work, and their rate of pay. Under a self-directed personal assistance services state plan option, beneficiaries could receive a cash allowance to hire their own workers to help with such activities as bathing, preparing meals, household chores and other related services that help a person to live independently. Allotments also could be used to purchase items that help foster independence such as a wheelchair ramp.

The proposed rule can be downloaded from the CMS website:

www.cms.hhs.gov/MedicaidGenInfo/Downloads/CMS2229P.PDF

Truly Personal Attendant Care

Margaret (Peg) A. Nosek, PhD, Executive Director, Center for Research on Women with Disabilities, Houston, Texas, mnosek@bcm.edu, www.bcm.edu/crowd/

Part of my daily morning meditation is to give thanks and hold in the Light my team of attendants – past, present and future. They are the key to my survival and my “thrival.” Without them I could not live one hour; they make possible my productivity and my joy.

My household consists of me at the helm (when I feel like it) with Perla, my ace Number One helper for the past 12 years, and her three children: Aldo, who is almost 6; Gina, 4; and Edwin, 18 months, who live in the now three-year-old upstairs addition. Perla gets me up and works until three o'clock every weekday.

Gaby joined us last summer to be my weekday afternoon and night-time helper. She and her one-year-old daughter, Shabana, live downstairs with me. My third helper, Amalia, has been with me for six years and comes in to work on the weekends. In addition, I have several women who have worked for me in the past who are available to substitute when necessary. The chaos is delightful.

A combination of advertisements in the Spanish-language newspaper and word-of-mouth referral among friends has brought these ladies to me. My ability to speak Spanish and the fact that I have a house large enough to accommodate them has met their needs as well as mine. I pay \$50 for one half-day shift, or \$100 for a 24-hour period.

Calculating this as an hourly rate would indicate that I pay less than minimum wage, but there are many other benefits that I offer. I provide housing and all of the accompanying expenses, including food. There are large parts of the day when I ask for nothing other than their presence in the house, so they are able to take care of their children and their other needs in what would technically be considered “work” hours.

I require no qualifications on their part other than honesty, integrity and a willingness to learn. I prefer to have Perla do all of the training of new attendants. The total expense for supporting three full-time workers consumes two-thirds of my total income. Because I am employed, albeit only part-time, I am not eligible for any government assistance.

Life was a lot easier, and my attendant needs were much less before I used a trach. Spinal muscular atrophy, which has shown its presence in my life gradually since birth, has had its most life-threatening effect on my muscles of respiration.

The nasal mask and bilevel ventilator I used during the night for 10 years were becoming less and less effective. Finally, seven years ago, a respiratory infection evolved into pneumonia and caused both of my lungs to collapse.

Since I was already in the hospital, the emergency tracheotomy was conducted just in time to save my life. There was no hesitation in my consenting to have the procedure, much to the dismay of the resident on duty; I had made the decision and communicated it to my physicians many years ago that living by whatever means was my priority.

Left to right: Edwin, Peg, Aldo, Rosemary Hughes holding Shabana, Perla holding Gina.

After two weeks in the ICU, I had eight weeks of comprehensive rehabilitation at The Institute for Research and Rehabilitation (Houston) to learn how to live with my new method of breathing. The outstanding respiratory therapists taught my attendants how to do suctioning and trach care and operate the new ventilator, the nicely compact and relatively quiet LTV®950 (www.pulmonetic.com). There is one on the back of my power wheelchair and another one in the bedroom.

It's amazing how clearly you can think when your brain gets enough oxygen. With the trach my productivity has soared, and my health is more robust. I have no desire whatsoever to wean off the ventilator.

In the first several years I had two hospitalizations because of respiratory infections. Since then I have been able to manage them at home with oral antibiotics. However, my best defense is using alternative therapies, including vitamin C, echinacea and a variety of medicinal teas that aid breathing.

As my wise pulmonologist advised me – some pretty heavy bacteria are constantly residing in the trach and the best way to hold them at bay is to eat well, sleep well and stay active.

My attendants have a good routine for changing the filters and cleaning the circuits that connect to the trach. I asked a colleague of mine who specializes in prosthetic infection the best way to minimize problems with a trach. He advised me to clean it with ordinary antibacterial soap once or twice a week. I ran into a lot of problems with the hard plastic trach tube rubbing on my curved trachea (due to scoliosis) and creating an irritation that attracted bacteria. Switching to



a flexible trach tube made by Bivona has solved that problem nicely. It is such a relief to know that my attendants can help me raise the secretions, as long as my machines are in working order, that is.

I'm still chicken when it comes to traveling. Although I'm not anxious to resume the insane travel schedule I followed at the midpoint of my career, I would like to engage in more travel for fun. On an adventurous whim, two of my attendants, two of their kids and I took off on a road trip last summer to Matamoros, Mexico. The folks in the markets gradually overcame their shock at seeing someone using a ventilator with a pyramid of kids riding on the back of her wheelchair.

I still work parttime. This enables me to continue my career, maintain my private health insurance, and receive Social Security disability insurance plus long-term disability benefits from my employer. Whenever I earn any extra income from consulting or writing, the long-term disability payments are reduced by half of what I make.

I continue my work on developing health promotion interventions for women with disabilities while enjoying my kids, my garden and all the fun things I let myself do now. I am forever grateful for this second chance at life. ▲

Take Charge, Not Chances: In Practice

Lawrence C. Becker, PhD, Roanoke, Virginia, lcbecker@bookwork.net



Larry Becker

I use mechanical ventilation for sleep, and for rest. I've been at this for a long time – since the polio epidemic of 1952. My health and my equipment have been pretty stable except for the fact that I switched from a chest shell to a BiPAP® in 1994. Of course all sorts of things, including breathing-related ones, are getting harder as I age (I am 68), but otherwise my life is going along fairly smoothly.

I thought I was pretty well prepared for emergencies of various sorts. So when I downloaded the **Take Charge, Not Chances** documents and started to do them, I didn't expect that it was going to take much time. After all, I have a backup unit, as well as a backup power supply. I have a good internist whom I see regularly. He and the local medical center have the relevant information about my medical condition, along with copies of my advance medical directive. We all have a good understanding about oxygen, anesthesia and positioning issues, among other things. If none of that had been in place, the process would have been harder. (I regret to say that 10 years ago, none of the preparations would've been in place except for the backup unit. Some things get shoved aside.)

But even so, as it turned out, there were significant gaps in my supposedly good, recent planning:

In all these years, I had never signed up with a medical alert service, or bothered to assemble a complete set of documents to take with me on business trips.

I had never made sure that the fire department, and local paramedic service, had the relevant information about my condition.

I had never discussed emergency medical care issues with the health care aide who travels with me.

And actually, my wife and I had never had a sustained conversation about these matters. For 40 years, we've simply dealt with things as they came up.

My pulmonologist had retired three years ago (without my permission), and I hadn't gotten connected with another one.

I've now fixed all of this, and I'm very grateful to have had these documents. They did a great deal to organize my thinking about preparing for emergencies, and they did even more to motivate me to go beyond the preparations I had previously made. That motivation was important, because it turned out to require some significant effort over several weeks.

Several matters were particularly instructive, and different from what I anticipated.

■ **Medical alert record.** For one thing, it turns out you can negotiate with the medical alert people about how precisely to describe your condition so as to get what's most important engraved on the bracelet. At least MedicAlert®, the system I chose, does this through their medical review committee. It takes a few days to get the answers, but it's worth it, because the standard options they offer are not very useful for neuromuscular ventilator users. MedicAlert® will also upload all of these **Take Charge, Not Chances** documents after you fill them out, and the people on their answer-line will then be ready, 24/7,

to download them or fax them or read them aloud to any EMS or medical personnel who need them. This alone simplifies a lot of things about travel. DONE.

■ **Fire and rescue.** I called to arrange a time to drop off the documents to the local firehouse, which also houses the EMS people. One thing led to another, and we finally decided that it was better for them to get a group together to come out to our house. A very good reason for this is that (as they explained) if we call 911 we might get any of three nearby rescue squads. Another reason was their desire to look at the house with respect to ease of access and safety generally.

So we arranged a time, and five people from three different stations arrived. They found the **Take Charge** documents very useful, especially with respect to oxygen use, positioning, normal blood gas values, and contact information. They suggested that I place a summary on the refrigerator (where they always look for instructions), or even **in** the refrigerator (in something they called the Vial of Life, which they also look for).

They seemed satisfied to have the documents and to have spotted the ready-packed case containing my backup ventilator and packet of medical documents. It was also reassuring to have their enthusiastic blessing about the entrances and exits and general safety of the place. I got the idea that they might have liked to practice lifting me from the floor onto a gurney, but I changed the subject. DONE.



Photo credit: Sam Dean/The Roanoke Times

■ **Conversations with caregivers.**

Useful. A good idea. ONGOING.

■ **Pulmonologist.** I asked my internist to recommend a pulmonologist who has experience treating neuromuscular problems requiring mechanical ventilation. He suggested several. One in particular interested me.

“These documents are excellent,” said my new pulmonologist. He was looking at them during my recent office visit, after the physical and baseline studies. He signed the “Patient’s Vital Information for Medical Staff” document, and immediately gave me not only his home phone number but his cell phone as well. (When was the last time a physician gave you his cell phone number?) And he wrote instructions on a prescription form that he wants me to carry in my wallet. He then made copies of the IVUN materials for my chart, and additional blank copies for some other neuromuscular patients.

“Who did this?” he asked about the documents, and then answered his own question by turning to the back page. “Good for them,” was his final remark. (He doesn’t waste words.) DONE. ▲



Download the portfolio
at [www.ventusers.org/
edu/valnews/
VAL_21-4pAll.pdf](http://www.ventusers.org/edu/valnews/VAL_21-4pAll.pdf)

From Around the Network

Judith R. Fischer, IVUN Information Specialist, info@ventusers.org

BiPAP® AVAPS™ (Average Volume Assured Pressure Support) is a new bilevel ventilator from Respironics, Inc. that automatically adjusts the pressure support level to maintain a consistent tidal volume.

According to Elaine Lesnak, RRT, Home Respiratory Care Division at Respironics, "AVAPS combines the comfort and leak compensation of a pressure mode with the safety of a guaranteed volume."

Weighing only 4.2 pounds, BiPAP® AVAPS™ is simple to operate and has an integrated heated humidifier. BiPAP® AVAPS™ will eventually replace BiPAP® Synchrony™. www.respironics.com



The new AVAPS™ is highly recommended for people with neuromuscular conditions. According to Sairam Parthasarathy, MD, a sleep physician at the University of Arizona in Tucson, the advantages of AVAPS™ are:

- ◆ guaranteed ventilatory support during progressive respiratory changes,
- ◆ guaranteed ventilatory support during positional changes during sleep,
- ◆ assurance of tidal volume, and
- ◆ alarms that indicate that the tidal volume is not being met.

Respironics, Inc. has been acquired by **Royal Phillips Electronics** in a deal expected to be completed early in 2008. Respironics will become the headquarters for Phillips Home Healthcare Solutions group within Phillips Healthcare. The senior operating leadership of Respironics is expected to remain to continue to lead and manage the business.

Noninvasive assisted breathing on TV. Josh Benditt, MD, and Louie Boitano, RRT, of the Northwest Assisted Breathing Center at the University of Washington in Seattle, discuss noninvasive breathing options, equipment and set up of "sip" ventilation for people with neuromuscular conditions. One of their patients who has Duchenne muscular dystrophy is featured using the sip technique. Go to www.uwtv.org/programs, click on "Program Library," then click on "Programs by Title," scroll down to "Non-invasive Assisted Breathing," and click again. The program is 27 minutes.



Beyond Sticks and Stones: How to Help Your Child with a Disability Deal with Bullying

More than 160,000 children, many with disabilities, miss school each day to avoid harassment and intimidation by classmates. This book assists parents in helping their child address the problem of bullying. To order send \$6 (USD only) to PACER Center, 8161 Normandale Blvd., Minneapolis, MN 55437-1044. ▲

2008 CAMPS FOR VENTILATOR-ASSISTED KIDS

March 29-April 4. VACC (Ventilator-Assisted Children's Center) Camp. Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vaccamp.com.



Dancing in chairs at Miami's VACC.

Want to be part of an experience of a lifetime?

Volunteer to assist at a camp near you.

June 1-6. Trail's Edge Camp. Mayville, Michigan. Contact Mary Buschell, RRT, Camp Director, 231-228-3371, mdekeon@med.umich.edu, www.umich.edu/~tecamp/

June 1-7. Camp Pelican. Lion's Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343, cathyallain@cox.net, www.camppelican.org.

June 8-13. Fresh Air Camp. Camp Cheerful, Strongsville, Ohio. Contact Kathy Whitford, MSN, PNP, Cleveland Clinic Foundation, 216-721-7159, whitfok@ccf.org, www.freshaircamp.org.

June 11-15. Camp Inspiration at Double H Hole in the Woods Ranch. Contact Tara Bogucki, Admissions Coordinator, 518-696-5676 ext. 222, theranch@doublehranch.org, www.doublehranch.org. Application deadline: April 15.

June 16-20. CHAMP Camp. Recreation Unlimited, Ashley, Ohio. Contact Camp Administration, 317-679-1860, admin@champcamp.org, www.champcamp.org.

June 22-26. Pennsylvania Vent Camp. Camp Victory, Millville, Pennsylvania. Contact Robin Kingston, MSN, CRNP, 717-531-5337, rkingston@hmc.psu.edu.



Smiles courtesy of Camp Victory, Millville, Pennsylvania

July 4-7. Light the Way Camp. Children's Harbor, Alex City, Alabama. Contact Kara Bishop, 205-370-9605, karabishop@ventkidsofalabama.com, www.ventkidsofalabama.com. ▲

The Pandemic Ventilator Project

Clarence Graansma, Senior Renal Technologist, Kitchener, Ontario, experienced the 2003 SARS epidemic. Canada takes its pandemic planning very seriously, and in a meeting at the hospital where he is employed, he contemplated what he would do if a friend needed a ventilator during a possible bird flu pandemic and none was available.

Could he build one? Recognizing he could not, Graansma started a blog in February 2007. In addition to raising awareness and lobbying governments to develop realistic plans, the blog's objective is to gather information to build prototypes of ventilators that could be quickly made from commonly available components.

To review the archives and join the conversation, go to <http://panvent.blogspot.com/>

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- APRIL 10-12** **Eighth Annual Focus on Respiratory Care and Sleep Medicine Conference.** Opryland Hotel & Convention Center, Nashville, Tennessee. www.foocus.com
- MAY 16-21** **American Thoracic Society International Conference.** Toronto, Ontario, Canada. www.thoracic.org
- JUNE 19-22** **FSMA Families and Professionals Conference.** Boston Park Plaza, Boston, Massachusetts. www.fsma.org
- JUNE 22-24** **International Conference on Chronic Ventilated Patients: Multidisciplinary Management from ICU to Home** under the auspices of Reuth Medical Center. Dan Panorama Hotel, Tel Aviv, Israel. Keynote speakers include J. Milic Emili, Roger Goldstein, Doug McKim, Canada; Enrico Clini, Italy; Pamela Cazzolli, USA. Contact Hila Vakrat, Conference Coordinator; +972-3-5767723; Hilav@congress.co.il, www.congress.co.il/ventilation-reuth08
- JULY 17-20** **Parent Project for Muscular Dystrophy.** Lowe's Hotel, Philadelphia, Pennsylvania. www.parentprojectmd.org
- SEPT. 18-20** **ALS/MND Nursing Symposium.** Radisson Hotel, Chicago, Illinois. www.lesturnerals.org/educationalactivities.htm#nursing
- OCT. 4-8** **European Respiratory Society Annual Congress.** Berlin, Germany. www.ersnet.org
- OCT. 25-30** **CHEST 2008.** American College of Chest Physicians. Philadelphia, Pennsylvania. www.chestnet.org
- NOV. 3-5** **19th International Symposium on ALS/MND.** Birmingham, England. www.alsmndalliance.org
- DEC. 13-16** **54th International Respiratory Congress of the American Association for Respiratory Care.** Anaheim, California. www.aarc.org ▲

Call for Proposals: IVUN's Fifth Research Grant

Are you a researcher? Do you have an innovative idea for investigating neuromuscular respiratory disease? Guidelines for applying are available at www.ventusers.org/res/rfcall.html

Dates to Remember:

Monday, March 3, 2008

Deadline for Phase 1 application

Monday, April 14, 2008

Invitation to submit Phase 2

Monday, June 16, 2008

Deadline for Phase 2 application
(if invited by IVUN)

Monday, November 10, 2008

Announcement of recipient

Thursday, January 15, 2009

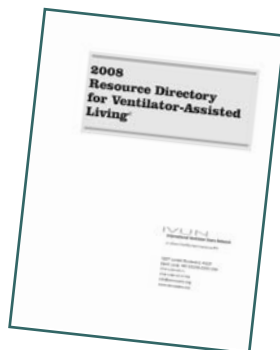
Receipt of \$15,000

Wednesday, July 15, 2009

Receipt of \$10,000

IVUN's Resource Directory for Ventilator-Assisted Living 2008

is now available online at www.ventusers.org/net/VentDIR.pdf. (While there, check out the Home Ventilator Guide at www.ventusers.org/edu/HomeVentGuide.pdf.)



Published since 1989, this comprehensive resource for linking to information about long-term assisted ventilation includes:

- Health Professionals
- Listservs for Ventilator Users
- Ventilator Equipment and Aids
- Manufacturers' Addresses, and
- Related Organizations, Associations and Foundations
- Facilities with Long-Term Ventilator Units

To be listed in the *Resource Directory for Ventilator-Assisted Living*, send your contact information to info@ventusers.org with "Resource Directory" in the message line.

To order a print Directory, send \$12 (USA); \$14 (Canada and Mexico); \$16 (Overseas air) in USD only, to our address on page 2.

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Rates Effective July 2007

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Signature _____

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