

Meet Jacob Gapko

Jacob Gapko, Eau Claire, Wisconsin, gapkoja@yahoo.com

I have Duchenne muscular dystrophy, but I am considered an “outlier” case since I walked until age 14. I used a manual wheelchair during high school and got my first power chair at age 17. I have used a BiPAP AVAPS at night since age 22 and the LTV®950 (see Ask the Expert, p. 6) during the day for the past three years, beginning at age 32. Two agencies provide me a total of seven hours of personal care per day at home; my parents provide overnight care and fill in when agency workers are unavailable.



Jacob Gapko

In fall 1996, I entered the University of Wisconsin–Eau Claire, majoring in physics with minors in mathematics and library science. In summer 1999, sponsored by the EntryPoint program of the American Association for the Advancement of Science, I served as an intern at the National Aeronautical and Space Administration’s (NASA) Goddard Space Flight Center (GSFC) Library in Greenbelt, Maryland. The EntryPoint program is designed for persons with disabilities studying in the STEM (Science, Technology, Engineering and Mathematics) fields.

I created GSFC’s first web channel on Engineering and Technology, primarily for research scientists at GSFC. Aggregating resources from GSFC, NASA centers and other worldwide materials on engineering and technology, this single portal gives scientists and engineers at GSFC and elsewhere centralized access to information necessary for their projects.

During January 2000, I remotely created the Space Science web channel for the GSFC library on my home computer, again combining worldwide space science resources into a single accessible resource.

I graduated from UW–Eau Claire in May 2001 with my B.S. in physics and completed UW–Milwaukee’s online Master of Library and Information Science program in December 2002.

My first professional job was as the cataloger at the Chippewa Valley Technical College (CVTC) library. While working at CVTC, I applied for and received a Carnegie–Whitney Award from the American Library Association to write *Children and Young Adults with Muscular Dystrophy: An Annotated Bibliography* (<http://quest.mda.org/article/children-and-young-adults-muscular-dystrophy-annotated-bibliography>). The bibliography provides a clearinghouse of books by and about young persons with muscular dystrophy for use by educational and health care professionals, family members and persons within the MD community.

I am currently enrolled in the Ph.D. program at UW–Madison in Library and Information Studies, minoring in Science and Technology Studies, and I am working on a literature review for my dissertation. I am indebted to my father who sacrificed three years of his retirement to commute with me to UW–Madison and care for me. ▲

From Around the Network

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

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.

Ventilator-Assisted Living

August 2012, Vol. 26, No. 4

ISSN 1066-534X

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Special thanks ...
Judith R. Fischer, MSLS

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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.

New Products

Amara, a new full-face mask from Philips Respironics, is smaller and lighter than most traditional full-face masks. The mask cushion snaps into the mask frame. Available in petite, small, medium and large sizes, only in the USA.

www.healthcare.philips.com/us_en/homehealth/sleep/amara/index.wpd

Quality of Life Grants

CMMS Deshae Lott Ministries is accepting quality-of-life grant applications from individuals needing funds to live outside of an institution or to supplement their medical coverage (if grant would not disqualify the individual from his or her other means of medical coverage). Deadline is November 1. Grant awards will be announced by the end of the year. www.deshae.org/cmms/qlgrant.pdf

Care and Management of Ventilator-Assisted Children

Guidelines for Pediatric Neuromuscular Weakness

Recently released is an excellent and comprehensive resource: "The British Thoracic Society (BTS) guideline for respiratory management of children with neuromuscular weakness." Lead author is Dr. Jeremy Hull, Oxford University Hospitals, NHS Trust.

Sections include respiratory complications of neuromuscular weakness; identification of children at risk of respiratory complications; airway clearance and respiratory muscle training; types of assisted ventilation; planning for surgical procedures; scoliosis; feeding and swallowing difficulties and transition to adult care. Also included are social and ethical considerations such as quality of life, palliative care and end-of-life care, in addition to an extensive bibliography and appendices.

The guidelines are available to everyone at www.brit-thoracic.org.uk/Guidelines/Children-with-Neuromuscular-Weakness.aspx. For more information, contact jeremy.hull@ouh.nhs.uk.

"Home Noninvasive Ventilation: What Does the Anesthesiologist Need to Know?" is a good companion to the BTS pediatric guidelines above. There are no practice guidelines on perioperative management of ventilator-assisted children, but this article, by a group of Canadian pediatric pulmonologists led by Karen Brown, MD, Montreal Children's Hospital, is a good beginning. It appeared in *Anesthesiology* 2012, 117(3), but is only available free to subscribers. Nonsubscribers can purchase it online at <http://journals.lww.com/anesthesiology>

The ways in which home noninvasive ventilators work in children (also relevant to small adults and those with poor respiratory muscle strength and drive) are thoroughly explained: triggers,

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Understanding Chronic Obstructive Pulmonary Disease (COPD): Part II

Zach Gantt, RRT, Director of Clinical Programs, and Chris Schlecht, CRT, CPFT, Director of Health Management Sales, Alana HealthCare, Nashville, Tennessee, Zach.Gantt@alanahealthcare.com, Chris.Schlecht@alanahealthcare.com

Chronic obstructive pulmonary disease (COPD) is one of the most complex chronic illnesses in the world and one of the most undertreated. It has one of the lowest levels of patient knowledge of all chronic diseases.

According to a study performed by the National Institutes of Health in 2009 polling 1,003 COPD patients, only 10% of those patients knew their forced expiratory volume (FEV1), but 79% knew their blood pressure reading. FEV1 is the maximal amount of air a person can forcefully exhale in one second and is as important to a COPD patient as blood pressure is for a hypertensive patient.

Only one in four COPD patients believes they were well informed about their disease and treatment options. COPD is the only major fatal illness in which the age-adjusted mortality rate is increasing, growing by 283% between 1979 and 2007, compared with coronary heart disease and stroke, which have decreased by 70% and 73% respectively.

To make managing COPD even more complicated, a large number of patients also have comorbidities. The most prevalent comorbid diagnoses are hypertension (55%), heart disease (52%), depression (37%) and diabetes (25%). Often, patients with COPD have multiple physicians caring for them, making it difficult to coordinate care.

In 2000, the Committee on Manpower for Pulmonary and Critical Care Societies first identified a shortage of pulmonary and critical care specialists. Their projections showed that by 2020, the critical care and pulmonary medicine workforce would fall short of the nation's needs by 22% and 35%, respectively. Due to this shortage of pulmonary/critical care physicians, management of the COPD population often rests with general practitioners. More than 60%

of physicians admittedly fail to provide their patients with basic disease education, nutritional guidance and home service coordination.

COPD Treatments

Treatment for COPD can come in the form of medication, equipment, breathing techniques, nutritional guidance and pulmonary rehabilitation, among others. None of these options reverses the disease but rather reverses or reduces the symptoms associated with the disease. Without proper education and implementation, the success rate of any type of treatment for COPD is low.

Medications and Vaccinations

Inhaled bronchodilators have been shown to alleviate symptoms, decrease exacerbations, and, for a period of time, improve health status. Short-acting bronchodilators such as Albuterol or Xopenex, also known as “rescue inhalers,” are recommended on an as-needed basis for acute symptoms. As the disease progresses and symptoms become more persistent, long-acting bronchodilators, or “maintenance inhalers,” such as Spiriva or Symbicort, may be required. Choosing between long-acting and short-acting

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What is a Bronchodilator?

A bronchodilator is a common medication used in the treatment of COPD. It works by relaxing and expanding the airways making it easier to breathe.

Bronchodilators are the preferred method of treatment for relief of acute symptoms of COPD and also help to prevent spasms of the lungs due to exercise.

Bronchodilators help to relieve bronchospasms and reduce airway obstruction. In doing so, more oxygen is distributed throughout the lungs and more of the waste product, CO₂, is removed, making it easier to breathe.

bronchodilators may depend on individual response. Using a combination of bronchodilators, rather than increasing the dose of a single bronchodilator, can improve their therapeutic effectiveness and decrease the risk of side effects.

Annual influenza vaccines can reduce the risk of serious illness, exacerbation and death in patients diagnosed with COPD and are recommended for elderly COPD patients. A pneumococcal vaccine is also recommended in order to prevent pneumonia.

Oxygen & Medical Devices

COPD patients (Stage 3 and/or 4) are commonly treated with long-term oxygen therapy. It is used when patients have low levels of oxygen in their blood (hypoxia) and is given both in the hospital and at home. Several studies show that using oxygen at home for more than 15 hours a day increases quality of life and helps people live longer.

The use of noninvasive ventilation (NIV) for Stage 3 and 4 COPD patients continues to command a breadth of promising research. A number of studies have demonstrated NIV's ability to increase one-year survival rates by 25%, two-year survival rates by 42% and to improve patient mobility and physical stamina. Furthermore, when combined with long-term

oxygen therapy, the use of NIV in the home has demonstrated cost-savings upwards of 35% due to reduced hospitalizations and reduced length of stay.

Education

Patient education has demonstrated the greatest area of opportunity toward effective COPD management. Health education for COPD patients includes knowledge about the disease, medication use/compliance, recognition and treatment of exacerbations and complications, and strategies for minimizing breathlessness. The greatest improvements in patient care and cost containment stem from effective education initiatives.

For the most part, COPD tends to be treated like an acute problem in what is often referred to as “the failed cycle of care.” Patients have an exacerbation or flare up, go to the emergency room, get treated with breathing treatments, steroids, sometimes BiPAP or, in severe cases, mechanical ventilation via intubation or tracheotomy. Once the exacerbation has diminished, they return home ill-prepared for the next exacerbation.

Research and innovations have developed that identify a variety of therapies and treatments proven to improve quality of life, reduce disability, lower mortality and drive down cost. However, a complex but fractured health care system has failed to adopt and implement many of these evidence-based solutions. In 2001, the Institute of Medicine released a report concluding that the time frame from the point of research to the widespread diffusion and adoption of the results is at least 17 years, a timeframe deemed by many to be unacceptable.

Like other chronic conditions the solution starts with widespread knowledge and understanding of the disease and treatment options. The next step

Zach Gantt, RRT, has nearly 20 years of respiratory care experience in health care, specializing in disease management, outcomes-based services and patient-centered care. He maintains a thriving health care education consulting business and serves as a critical care paramedic instructor at Roane State, and is a board member and chapter president for the Tennessee Society for Respiratory Care.

Chris Schlecht, CRT, CPFT, has 20 years' experience in respiratory care and cardiopulmonary medicine. He earned his degree through the U.S. Army Academy of Health Sciences and started his career working in the cardiopulmonary diagnostic area. After entering home care in 2000, he joined Alana in 2010, where he has served as branch manager and currently as director of health management sales.

is to engage the patients and ensure there is mutual accountability. Simply put, all parties involved in the care and well-being of the patient, including the patient, must take responsibility and must be held accountable for his or her action. Unfortunately, there is no cure for COPD, but it is a very manageable disease with patient involvement.

According to Aristotle, “The whole is greater than the sum of its parts.” Likewise, traditional treatments for COPD are fragmented. By combining all of the treatment options into an integrated disease management program, studies show outcomes improve greatly.

- 57% reduction in hospital emergency admissions
- 59% reduction in hospital admissions
- 39% reduction in unscheduled general practitioner visits
- 73% reduction in general practitioner visits
- 20% increased medication adherence
- 10% improved pulmonary gas exchange

The biggest challenge with integrated disease management programs is re-imburement; there is no standardized reimbursement for disease management in homecare. Because of this, the burden has been largely placed on the insurance companies to adopt programs for their members. One of many problems with this is lack of standardization.

Comprehensive Respiratory Outcomes Management

Comprehensive Respiratory Outcomes Management (CROM) is Alana Health-Care’s proprietary disease management program for respiratory patients, designed to break the cycle of failed care by rehabilitating recently hospitalized patients and preventing re-admissions and, where possible, preventing hospitalizations altogether.

CROM is comprised of two major components – Outcomes Management and Respiratory Therapy Management – both integrated using education, patient engagement and high-touch clinical care through which new technology creates a health care system that is more comprehensive, better coordinated, and empowers patients to take control of their own health status.

CROM utilizes experienced respiratory therapists to work with patients and their providers in creating a new culture of patient care through therapy management, education and outcomes. Each respiratory therapist manages a small number of patients and spends a minimum of 12 hours in the patient’s home over several visits during the first month alone. During this time the therapist and patient build a foundation for education, shared responsibility and therapy adherence.

Following the first month of participation, respiratory therapists continue to stay in close contact with the patient with frequent scheduled visits. In addition to planned in-home visits, patients have 24/7 access to respiratory therapists. Additionally, because CROM is designed to work with patients in their homes, the program is highly mobile and not restricted by geographic limitations.

Education, coordination, collaboration and quality care: None of these terms seems too complicated, but implementing such seemingly easy tasks in the care of COPD has proven to be difficult. In recent years the first signs of reimbursement for quality and proactive care, instead of quantity and reactive care, have surfaced. One can only hope adoption and widespread diffusion of COPD disease management does not take the average 17 years. ▲

Resources:

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QUESTION: I have seen pictures of mouthpiece ventilation, but would like more details on how to set it up. Can someone describe theirs?

Ask The Experts

ANSWER: Jacob Gapko, Eau Claire, Wisconsin, gapkoja@yahoo.com

Here is the setup I use with my LTV® 950 ventilator which has specific settings for the NIV mode.



My setup starts with an air tube straw, connected to a 3.5 mm adapter ET, connected to a patient circuit, connected to a bacterial/viral filter and

finally to an elbow adapter. A microphone gooseneck supports the setup and holds the straw close enough to reach.

Manufacturers, part numbers, and contact information:

- air tube straw (disposable), part # 32698 (10 Pack), part #32662 (100 Pack) from Therafin. www.therafin.com/controlaccessories.htm. I obtain mine drop-shipped from Express Medical, 636-349-8448. Ask for Kris Winston.

- 3.5 mm x 15 mm adapter ET, part #501003035 from Rusch, part of Teleflex Medical. www.teleflex.com

- patient circuit with PEEP, 22 mm, from CareFusion SPU (P/N 10820X10). www.carefusion.com or Customer Service, 877-754-1914.

- elbow adapter, standard 22 mm I.D. x 22mm O.D., Cat. No. 1641, from Hudson RCI, part of Teleflex Medical. www.teleflex.com

- bacterial/viral filter, Cat. No. 1605, from Hudson RCI. Go to www.hudsonrci.com/How/locator.asp for distributors near you, plug in your ZIP code or contact Teleflex Medical directly, 866-246-6990.

Marilyn Keen, the respiratory therapist at my home health company, Reliable Medical Supply, will be glad to answer questions about the setup. Call her at 763-255-3853. www.reliamed.com.

Since secretion clearance is an important part of NIV, I have incorporated the CoughAssist® and the InCourage™ airway clearance systems into my daily routine. Using both takes 30 minutes per session three times per day when I am healthy. I use them more often when I get a respiratory infection. I also have a standing order for antibiotics in case I cannot get in to see my doctor. Without antibiotics, it is very easy for a respiratory infection to develop into pneumonia, even when it starts as a viral infection. In the last decade I have been hospitalized only twice. ▲

From Around the Network continued from page 2

interfaces, leaks, circuitry, re-breathing, to name a few. In addition, the design features of home ventilators as Class I and Class II Medical Devices by the Organization for International Standardization are listed.

Recommendations include both preoperative and postoperative management of these children (involving close monitoring of oxygen saturation and cardiorespiratory status); and transition back to home NIV system and liaison with home ventilation program *before* dis-

charge. To contact Dr. Brown, email roula.cacolyris@muhc.mcgill.ca.

Flu Vaccine 2012-2013

The U.S. Food and Drug Administration (FDA) voted to adopt the World Health Organization's recommendation for the Northern Hemisphere's 2012-2013 seasonal influenza vaccine. The vaccine viruses include: H1N1 virus (same as used in the 2011-2012 vaccine), H3N2 vaccine and B vaccine.

To meet estimated demands of the upcoming flu season, drug manufacturer Novartis launched delivery

of more than 30 million doses of its seasonal flu vaccine – Fluvirin® – to provide the earliest possible protection against the flu. Fluvirin vaccine, reformulated to include the two new strains, is FDA-approved for patients 4 years of age and older. www.cdc.gov/flu/about/season/upcoming.htm

People are advised to get the vaccine as soon as it becomes available, and local pharmacies are already advertising “flu shots.” For more on how you can protect against flu, go to www.flu.gov. ▲

Schedule for Educational Conference Calls Announced

Topics and times for IVUN's series of hour-long educational sessions via the telephone starting in early fall have been set. The call is free, but reservations are required, and available space will be first-come, first-served. To reserve your place to participate in the call, send an email to info@ventusers.org or call 314-534-0475.

Wednesday, September 12, 2012 at 1:00 CDT

Switching from the PLV-100, 102 (or other volume vent) to the Trilogy, with representative from Philips Respironics.

Wednesday, October 24, 2012 at 1:00 CDT

Other Options: Switching from PLV-100, 102 (or other volume vent) with Cyndy Miller, RRT, Respiratory & Monitoring Solutions, Covidien, Costa Mesa Facility (formerly Newport Medical) and a representative from CareFusion.

Tuesday, November 13, 2012 at 1:00 CT

How I Became an Active Patient Advocate with Dr. Norma Braun, Clinical Professor of Medicine, Columbia University, College of Physicians & Surgeons; Senior Attending, Pulmonary/Critical Care/Sleep Division, St. Luke's-Roosevelt Hospitals, New York, New York.

Third week in January 2013

Tell Me About a Trach Before I Need One with Linda K. Dean, RRT, Educational Consultant and Clinical Specialist, Passy-Muir, Inc.

Third week in February 2013

How do I know when I need a Trach? With professional to be announced.

Do you have suggestions for other topics? If so, please send them to info@ventusers.org.
These educational sessions are supported by the March of Dimes.



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The eight-page newsletter will be sent electronically in February, April, June, August, October and December. (IVUN Members without email access may request print copies by contacting IVUN). Members will also receive an electronic *IVUN Membership Memo* in alternate months. To become a Member, complete this form. Memberships are 100 percent tax-deductible.

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How to contact IVUN ... International Ventilator Users Network (IVUN), An affiliate of Post-Polio Health International (PHI)
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