

Matt King is Pursuing His Dreams

Candy Wasserman, Marketing Communications Manager – Ventilation, ResMed Ltd., Bella Vista, Australia, candyw@resmed.com.au

Matt King was injured in his first professional rugby league match in 2004 at the age of 17. He broke his neck at C3-C4, and spinal shock went up to C2 which left him paralyzed from the neck down and completely dependent on assisted ventilation. He is trached and uses suctioning and regular nebulizers to keep his chest clear.

Matt left the hospital in 2007 with two Breas 403s, but was always on the lookout for a smaller device that was more convenient and less cumbersome. Matt learned about the Elisée 150 by chance in a newspaper article and contacted ResMed. He found that the Elisée 150 fit his lifestyle, and he purchased two of them.

Key features that attracted Matt to the Elisée 150 were its size and weight – it can easily and discreetly be stowed on the back of the wheelchair without the need of a vent tray, and it is reliable.

The Elisée 150 has enabled Matt to travel, going on a cruise in the Mediterranean last summer with the use of three external batteries (supplementing two internal batteries) keeping him on the move. Matt also flew to Sweden to go skiing, using his Elisée 150, which stowed easily under the seat in front of him. He flew on Virgin Atlantic, which he reports was

great in assisting with the organization of his flights.

“During the flight, I simply used the internal and external batteries on the ventilator, but brought my second ventilator as hand luggage in case there was a problem.”

At home, Matt keeps one Elisée 150 device permanently on his wheelchair and the other by his bed.

Matt has followed his ambitions and dreams and decided to pursue law studies after his accident. He completed his bachelor's degree in law in 2009 with flying colors. He is currently undertaking his Legal Practice Course in preparation for the master's degree in law with the intention of moving to London on completion of his studies to pursue a successful career in law.

Matt has not let mechanical ventilation get in the way of living his everyday life. He gets around by car, equipped with a ramp at the back to allow him to get in easily and a lock-down mechanism to secure the chair to the plate. He is able to move around easily and quickly.

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Matt lives in Langford, England, with his parents, younger brother and two dogs.

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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From Around the Network

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

New Products

INTERFACES

Swift™ FX for Her is another ResMed customized nasal pillows mask for women. The flexible design conforms to facial contours and movement by the wearer. Soft silicone headgear cushions the face and is easily adjusted by the headgear buckle. Airflow is directed away from the user and bed partner. Available in XS, S and M sizes to better fit female users. www.resmed.com

ComfortGel™ Blue is a new nasal interface from Philips Respironics that offers a lower profile exhalation port and an improved forehead pad to reduce pressure points. Available in four sizes. www.healthcare.philips.com/main/homehealth/sleep/

VENTILATORS

Puritan Bennett™ 560 portable ventilator is now available in the UK, Europe, Australia, Canada, and Asia. (It has not received FDA clearance in the United States; the Puritan Bennett™ 540 is the U.S. model). Compact, lightweight (9.92 lbs., 4.5 kg), and quiet (<30 dBA), the PB 560 contains an internal lithium-ion battery that can provide up to 11 hours of operating time. Many ventilation modes are offered for both NIV and invasive ventilation. Patient data can be transferred to the patient's physician. <http://respiratorysolutions.covidien.com/Ventilation/Ventilators/PuritanBennett560PortableVentilator/tabid/431/Default.aspx>

Trilogy200 is the latest model in the Trilogy series from Philips Respironics. Three triggering options (Digital Auto-Trak, flow, and proximal flow) are available for use with three circuit configurations. The circuits are a passive single-limb circuit with an exhalation port; a single-limb circuit with an active exhalation valve with proximal pressure; and a single-limb circuit with an active exhalation valve and proximal flow sensor. A six-hour battery system involves an internal and easily switched external battery. The unit is compact, weighing 11 lbs. (4.99 kg). <http://trilogy200.respironics.com/>

HT70® ventilator from Newport Medical Instruments, Inc. offers an easy color touch screen control, data download, and quickset alarm functions, as well as the NIV function in any mode. The 10-hour main internal battery has a "hot-swappable" feature and a 30-minute internal backup battery. Developed and manufactured entirely by Newport in California, the HT70 utilizes a new patented micro-piston technology. The compact unit weighs 17.4 lbs. (7.89 kg). Available worldwide. www.ventilators.com ▲

Ask The Experts

QUESTION: I am a polio survivor, and I don't want to start assisted ventilation because if I go on a bilevel device as suggested, I fear that my breathing muscles will become weaker. Is my fear misplaced?

This is a very good question. Many patients with respiratory muscle weakness have the same fear as yours. They all need to be reassured. Actually, there are very few chances that your respiratory muscles become weaker because of going on a bilevel device for noninvasive ventilation (NIV).

NIV is initially prescribed for nocturnal use. NIV is suggested when the ability of your respiratory muscles becomes insufficient to ensure normal gas exchanges, i.e., a sufficient oxygen intake (inspiration) with a sufficient discharge of carbon dioxide (expiration). NIV is designed to rebalance the exchange by boosting both the inspiration and expiration. In contrast to what you may think, your breathing muscles will be still working during nocturnal NIV. NIV is designed to be a nighttime assist that supports the work of your respiratory muscles. It is not designed to replace their work. In addition, your respiratory muscles will work without mechanical assistance throughout the whole day. That's why they do not get tired or weaker.

Clearly, the study of Ward et al. (Thorax 2005) demonstrated that patients who do not start NIV, despite the presence of abnormal gas exchanges at night, deteriorate within two years. As a consequence, not commencing NIV when suggested puts you at risk for deteriorating, while commencing NIV now does not put you at risk for weakening your breathing muscles. I hope this explanation will help you make an informed decision.

Michel Toussaint, PT, RT, PhD, Respiratory Therapist, Centre for Home Mechanical Ventilation, Inkendaal Rehabilitation Hospital, Brussels, Belgium, michel.toussaint@inkendaal.be

It is completely wrong to think that by starting noninvasive ventilation (NIV) your muscles will get weaker. The opposite is true. A basic principal of rehabilitation is to rest muscles then exercise them. BiPAP is a ventilator, but it is commonly used at pressure spans that inadequately rest the inspiratory muscles. The “pressure boost” should be at least 16 to 20 cm H₂O, so if the minimum expiratory pressure (EPAP) is set at 4 cm then the inspiratory pressure (IPAP) must be 20 to 24 for an adequate span. It is rarely done this way because doctors are more familiar with obstructive sleep apneas than they are with weak diaphragms.

The fact is, I consider BiPAP to always be suboptimal because you can not air stack to deep lung volumes when using it. This is why we always use portable ventilators that do not give EPAP, and we use full inspiratory muscle rest settings. When patients avoid NIV for fear of becoming dependent on it, their vital capacities (VCs) continue to decrease because their inspiratory muscles become exhausted. On the other hand, when they use the right ventilator at the proper settings, their VCs at least temporarily increase. I recommend that you find a doctor who understands these principles.

John Bach, MD, University of Medicine & Dentistry of New Jersey–New Jersey Medical School, Vice Chairman of the Physical Medicine and Rehabilitation Department, Medical Director of the Center for Ventilator Management Alternatives at University Hospital, Newark, New Jersey, NJMEDPhysicians@umdnj.edu

Are you a ventilator user or health professional with a question about home mechanical ventilation?

Send it to info@ventusers.org, and IVUN will find experts to answer it.

Kaine Rodriguez Thrives Thanks to Biphasic Cuirass Ventilation

Lupe Martinez, BSRC, RRT, RCP, AE-C, MSN HomeCare, San Antonio, Texas, guadalupemartinez@MSNHealth.com

Kaine Rodriguez was born with Prune Belly Syndrome, which affects the abdominal muscles, and which, in turn, affect the respiratory muscles. For Kaine, this means he cannot cough or breathe effectively.

Kaine spent the first nine months of his life in and out of the hospital, with previous admissions every three

weeks for respiratory distress, pneumonia and respiratory syncytial virus. With each hospital admission, Kaine's mother, Monica, watched as her son endured oxygen as high as 5 LPM with helium, CPAP or BiPAP, suctioning and respiratory treatments four times per day.



Kaine uses the biphasic cuirass vent system.

Photo credit: MitchCarr
http://everythinglubbock.com/search-fulltext?&nxd_id=52925

Monica recalls during one of her son's admissions, "I thought Kaine was going to die." The physicians gave her son only 72 hours to live. But Kaine is a fighter, and fortunately, Dr. Adaobi Kanu, his pediatric pulmonologist, decided to try the Hayek RTX biphasic cuirass ventilation system with him.

Now 13 months old, Kaine is smiling at his mother and progressing much like other infants his age: crawling, walking and putting on some much needed weight.

Monica attributes much of Kaine's progress to the Hayek RTX. She is excited that Kaine has not been hospitalized for respiratory problems since April 2010 when he was initially

placed on the Hayek. Monica believes it has also helped strengthen Kaine's abdominal muscles.

Currently, Kaine uses the Hayek for four hours at night and receives respiratory treatments twice per day. When Kaine gets sick, his mother increases his ventilator time from four hours to eight hours at night and increases the number of respiratory treatments.

MSN HomeCare has been providing much-needed skilled nursing care for Kaine in his home. He has responded so positively to the respiratory care, the biphasic cuirass vent system and to his loving family and nurses that everyone is looking forward to Kaine's continued progress.

Monica is interested in sharing her and Kaine's experience with others and can be reached in Lubbock, Texas, at 806-239-9500. ▲

For inquiries about MSN HomeCare in-home vent-assisted nursing, please call Jan Mawhee, 214-234-6834 or email JanMawhee@MSNHealth.com.

MORE on www.ventusers.org

IVUN has added In-Home Care Agencies and Respiratory Home Care Companies/DME to its *Resource Directory for Ventilator-Assisted Living*.

If you know businesses that should be listed, send their contact information to info@ventusers.org

What is Biphasic Cuirass Ventilation?

The newest method of negative pressure ventilation utilizes a chest shell or cuirass (widely used during the polio epidemics in the 1950s). This external, noninvasive ventilation system is called “biphasic cuirass ventilation” because it offers both inspiratory and expiratory breathing cycles. The biphasic cuirass ventilator works much like natural breathing by creating negative (breathing in) and positive (breathing out) pressures to help the lungs expand and contract. It can also provide both higher tidal volumes and higher frequencies (from 6 to 1200CPM). The custom-fitted clear plastic shells can be used on infants through adults.



Biphasic cuirass ventilation also offers respiratory treatments in a secretion-clearance mode that assists with coughing, similar to the CoughAssist®, and a vibration mode that delivers high frequency chest wall oscillation to loosen up secretions, similar to The Vest®.

The ventilator is a small power unit with a single hose that attaches to the cuirass. The patient can receive ventilation or respiratory treatments by simply switching the modes on the power unit.

Photos used with permission from United Hayek Industries, Ben Levin



The Hayek RTX biphasic cuirass ventilation system is manufactured by United Hayek Industries Medical Ltd, in London, England. It has been approved by the FDA for use in the United States and is Medicare/Medicaid reimbursable. (United Hayek also manufactured the Hayek Oscillator that was discontinued in the United States.)

For more information, go to www.unitedhayek.com or call 619-272-2333.

From Vent to Diaphragm Pacing System: Part III

Bill Miller, Leesburg, Florida, MaxNWM@aol.com,
<http://powerwheelchairusers.blogspot.com>

If you've followed my blog and pursuit of the NeuRx Diaphragm Pacing System™ (DPS), you know that I wanted to be using the DPS by now. However, I still don't have a surgery date, although that could be decided soon. Allow me to explain.

My pursuit of the DPS is slightly complicated by two things: (1) I take a blood-thinner medication to prevent blood clots, and (2) I also wish to have my cardiac pacemaker replaced during the same trip to the operating room.

Neither is all that complicated, but because I have to come off my blood thinner prior to surgery and get back to a therapeutic level afterward, I only want to have one surgery. Having two entirely separate surgeries would essentially double the chance that I could develop a blood clot or get an infection. I don't believe that my risk for developing a blood clot and/or getting an infection is very high, however, either could be fatal for person like me who is quadriplegic, since our immune systems are fairly compromised (and blood clots can be dangerous for people with fantastic immune systems).

My original choice of hospital – Shands at the University of Florida (my alma mater) – will not allow me to have both procedures concurrently. I think Shands wants to ensure that I'm medically stable on my cardiac pace-

maker before doing the DPS; however they did not explicitly state that. I believe I'm stable now; my pacemaker battery has been dead for several years, and even when working, it's only designed to kick in if my heart rate falls below 60 beats per minute, which I was told almost never happens. I even asked our state representative to encourage Shands and my insurance company to come to an agreement, but that was to no avail.

Fortunately, Florida has multiple facilities that are approved for DPS surgery. Two surgeons – one for the DPS and one for cardiac – at the Orlando Regional Medical Center (ORMC) are comfortable with concurrent procedures and recommended that to the pre-registration department. Pending approval, a surgery date may be set soon.

Like many things in life, this has been a lesson in both patience and perseverance – and I will NOT give up, even if ORMC cannot or will not do the procedures together. Stay tuned for Part IV ... ▲

MORE on www.ventusers.org

For more on Bill's pursuit of the NeuRx Diaphragm Pacing System™, see Parts I and II:

www.ventusers.org/edu/valnews/val_24-2apr10pAll.pdf

www.ventusers.org/edu/valnews/val_24-3jun10pAll.pdf

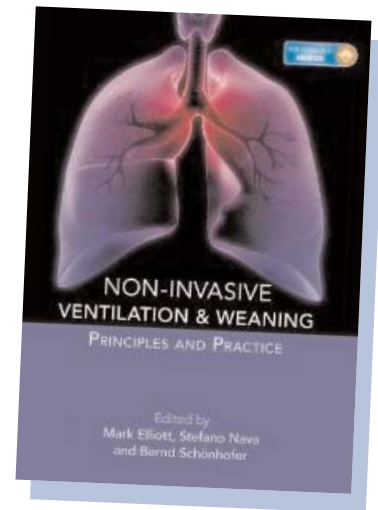
The NeuRx Diaphragm Pacing System™ provides electrical stimulation to the diaphragm (through the implantation of four electrodes) to cause it to contract, thus eliminating or reducing the need for a ventilator. It has been FDA-approved in the United States for people with spinal cord injury since 2008 and is awaiting FDA approval for use in people with ALS (it has been approved for ALS use in Europe). More information on the NeuRx DPS is available from Synapse Biomedical Inc., www.synapsebiomedical.com

New Reference Book on Ventilation

Non-Invasive Ventilation and Weaning: Principles and Practice, edited by Mark Elliott, MD; Stefano Nava, MD; and Bernd Schoenhofer, MD, with an expert group of contributors from 14 different countries, is new and vastly comprehensive. The 688-page reference work covers different applications for adult and pediatric non-invasive ventilation, and closely related techniques, both in hospital and at home. Well-organized topics also include NIV in cancer patients, in the elderly, in pregnancy, and in end-of-life care, as well as the effects of prolonged weaning and weaning failure.

The patient experience of non-invasive ventilation section includes “Psychological issues for the mechanically ventilated patient” by IVUN Consumer Advisory Committee Member Linda L Bieniek, in collaboration with Drs. Daniel F Dilling and Bernd Schönhofer.

Published by Hodder Arnold, London, UK, ©2010, the text is available for £149 through Amazon (www.amazon.co.uk/Non-Invasive-Ventilation-Weaning-Principles-publication/dp/0340941529/ref=sr_1_1?ie=UTF8&qid=1286803689&sr=8-1) ▲



Matt King is Pursing His Dreams

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What Matt likes the most about his Elisée 150 is its small size and the touch screen that provides comprehensive information. Alarm information is clear, meaning that when there is a problem, it is easily identifiable and resolvable, which also helps his attendants in their work.

Matt has two attendants around the clock, funded by the Primary Care Trust (part of the U.K.'s National Health Service that provides and coordinates health and social care systems). The agency overseeing his care runs advertisements in the local newspaper when needed and passes the applications on to Matt. “I then decide who I would like to interview and ask questions to them directly. At the conclusion of the interviews, I have the final decision as to whether the applicant is taken on.” Matt has a total of eight attendants, all of whom were interviewed, selected and trained by him.

Although Matt lives a busy life, he also contributes his time as a mentor through the Backup Trust (www.backuptrust.org.uk), an organization that provides activities, such as skiing,

paragliding, acting courses, etc., for people with spinal cord injury. He is paired up with young people who need advice, someone to talk to and someone who can answer their questions. This opportunity was not available when Matt was injured, but he feels that it would have been a good resource and is happy to give his time to help others.

He lives in Langford, England, with his parents, younger brother and two dogs. ▲

Ed. Note: The Elisée 150 is not available in the United States.

Calendar

NOVEMBER 21, 9:00 am-2:30 pm. Breathing & Sleep II.
Salk Institute for Biological Studies, La Jolla, California.
www.salk.edu/breathingandsleep

DECEMBER 6-9. AARC International Respiratory Congress.
Las Vegas, Nevada. www.aarc.org

DECEMBER 7-13. International Alliance of ALS/MND Associations, 18th Annual Meeting and 21st International Symposium on ALS/MND. J.W. Marriott, Orlando Grande Lakes, Florida.
www.alsmndalliance.org

DECEMBER 10, 6-8 pm. ALS/MND Nursing Mini-Symposium: Respiratory Care Update. J.W. Marriott, Orlando Grande Lakes, Florida. meeting@lesturnerals.org.

Meet Our Sponsor ...

RESMED 800-424-0737, www.resmed.com

ResMed is a leading developer and manufacturer of products for the treatment and management of acute and chronic respiratory conditions, specialising in NIV solutions for adults and children.

ResMed is committed to developing innovative, effective and easy to use solutions, to assist medical professionals in helping to improve the quality of life of patients.



Elisée 150

Meet Our Supporters ...

COVIDIEN 800-908-5888, www.covidien.com/PB540

At only 9.9 lbs., Covidien's new Puritan Bennett™ 540 portable ventilator is a weight off your mind. The real-time battery life indicator shows how much time you have until you need to recharge (up to 11 hours* – depending on settings and other factors).

* Fully charged battery at room temperature, set to $V_t=200$ ml (± 5 ml), $PIP=10$ cmH₂O (± 2 cm H₂O), $R_{tot}=15$ bpm. Level adjustments, environmental conditions and physiological characteristics of the patient affect battery operating time.



DALE

≡ Patient Care Incorporated™ 800-343-3980, www.dalemed.com

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PHILIPS

RESPIRONICS 800-345-6443, www.respironics.com

Philips Respironics is expanding the company's solutions for patients who suffer from chronic respiratory diseases with the introduction of the Trilogy200 ventilator. The Trilogy200 meets the needs of patients that require enhanced triggering sensitivity and monitoring in the home and alternative care settings. For more information: <http://trilogy200.respironics.com>



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