

Varsseveld, 5 November 2010

Subject: Flying with Ventilation

Dear Mrs. Emine Bozkurt,

I come back to you regarding our email correspondence we had in the previous weeks on the topic 'Flying with Ventilation'. As you know I took the initiative to set up a working group 'Flying with Ventilation'. I started this to address the increasing problems people with ventilation experience when wanting to travel by plane. People are refused to travel by airline companies often on a short notice, sometimes even one day before travelling, and people need to go through a complicated procedure to find out how to get approval to fly. Only a few airline companies allow people to use their ventilation on board without any problem.

As this problem is present in all EU countries (and beyond), I decided it would be best to try to solve this problem on the European level.

The reasons to address the problem 'Flying with Ventilation' are:

- People who need to use their ventilator on planes are experiencing many problems to get approval to fly.
- Airline companies don't have one policy regarding ventilator use. It is therefore complex and difficult to find out what the airline guideline regarding ventilator use is.
- Airline companies are often not clear in their communication to passengers with a ventilator. On their website they mention ventilators (also called respirators), but when one applies to get approval to fly it is denied.
- Some airline companies are inconsistent with their policy. On one flight it is no problem to fly and on another flight, with the same airline, one isn't allowed to fly.
- Some airline companies don't give a reason for denial to fly with them, even when all requests are fulfilled.
- Since 9/11 there is reluctance to allow unique machines on board let alone use them.
- Discrimination of passengers based on lack of awareness regarding ventilators/respirators when it comes to safety for other passengers, health problems of passenger with ventilation and liability.
- Many airlines confuse ventilation with oxygen use; if they address oxygen use they think they have 'done'.
- There is lack of communication between the medical department of an airline and the flight captain, who often isn't informed about the medical equipment taken on board and the reason why. This means that even when approval has been given, the passenger with ventilation additionally must inform the flight captain and crew when boarding. Since the flight captain is in total charge of the plane, (s)he still can decide to refuse the passenger to board.
- The problems with flying with ventilation means that people with ventilators/respirators can't fulfil their tasks in their job when long distance travel is involved. It is also difficult to fly to conferences, (inter)national meetings or one can't attend sport championships for people with a disability (e.g. wheelchair hockey).
- People with ventilators experience problems to book a flight for a holiday. They often can't fly with a budget airline and must book at more expensive airlines (if they allow them to fly).
- People with ventilators living on an island can be trapped in a country (Cyprus, Malta, UK, Ireland) or on the island they live (Sardinia, Sicilia, Corsica, Mallorca, Madeira etc.) when an airline doesn't accept them.

Your assistant Nejra Kalkan has send me several questions you are planning to ask the EU commission regarding the topic flying with ventilation with the request to look at it and to see if anything else should be added. We fully underline the questions you compiled.

- Is the Commission aware of the difficulties passengers who need ventilators are facing?
- There seems to be a lack of awareness regarding respirators/ventilators when it comes to safety for other passengers, health problems of passenger with ventilation and liability. Is the Commission able to raise awareness regarding this use to airline companies?
- Is the Commission planning to take any actions to combat the difficulties that people who use ventilators are facing?

Please read the information below for some further back ground information on ventilation and the working group.

What is ventilation?:

Respiratory health is a vital issue for many people with a neuromuscular disease. These diseases progressively weaken muscles, sometimes including those you use in breathing and coughing. Weak respiratory muscles may eventually lead to respiratory failure, a frequent cause of death in many neuromuscular disorders. To prevent this people with neuromuscular diseases, where also the diaphragm and respiratory muscles are affected, receive assisted ventilation to provide adequate air exchange. The primary problem in people with respiratory problems is that the breathing is too shallow and therefore needs extra mechanical support to breath normal (room) air and out. Most people with a neuromuscular disease have healthy lungs and therefore don't need oxygen such as people with cystic fibrosis and chronic obstructive pulmonary disease. Ventilation means mechanical support to get normal air in and out just like normal breathing.

The Working Group 'Flying with Ventilation':

The working group consists of people affected by a neuromuscular disease and active with the neuromuscular disease association in their country. Three people are at risk of needing ventilation in the future and three of the working group members use ventilation already for years. All three are fully dependent on it.

Stelios Stylianou is engaged in organisations which defend the rights of people with disabilities. He is President of the Youth section and member of the Board of Directors of the Cyprus Muscular Dystrophy Association.

Catherine Dinh – Dubuit has been asked by Association Française contre les Myopathies to represent them in this working group.

Ivanka Jovanovic is vice president of the European Alliance of Neuromuscular Disorder Associations (EAMDA), member of the Muscular Dystrophy Association of Serbia and executive director of the National Organisation of Persons with Disabilities in Serbia.

Evald Krog is President of Muskelsvindfonden in Denmark, a highly professional neuromuscular disease association with many members.

Dick Cochius is member of the neuromuscular disease association in the Netherlands. In spite of his severe disability caused by a neuromuscular disease, he always has been very active in all kinds of activities such as being the national coach of the Dutch wheelchair hockey team.

Maryze Schoneveld van der Linde is also severely affected by a neuromuscular disease. Since she receives enzyme replacement therapy her condition improved and she now works full time in 3 jobs: community worker, project manager at the European Neuromuscular Centre for the EU project TREAT-NMD and her own company Patient Centered Solutions – a consultancy in health and care.

All working group members are participating in this working group voluntarily and without any payment.

Situation of people using ventilation in the Netherlands:

In the Netherlands 1807 people are using ventilation. The past 19 years the number of people using ventilation has increased 9 times and shows a regular growth according to the expectations. People using ventilation have the following conditions: neuromuscular diseases (54%), chest deformity (21%), pulmonary and airway diseases (12%), apnea (10%) and others (2%). This number comes from the 4 centres of home mechanical ventilation in the

Netherlands. The registry is kept at the Vereniging Samenwerkingsverband Chronische Ademhalingsondersteuning (VSCA) where patient representatives, professionals involved in ventilation and the 4 centres of home mechanical ventilation of the university medical centres in Utrecht, Rotterdam, Groningen and Maastricht. Most people with ventilation live at home (84%), while others live in living units (11%) or nursing homes (4%).

Situation of people using ventilation in Europe:

The number of people using ventilation in Europe is an estimation as no registry is available. From the Centre of Home Mechanical Ventilation at the University Medical Centre in Utrecht I did receive an overview of the number of people receiving home mechanical ventilation in Europe (see attachment 1). In general one can say that more and more people requiring ventilation survive as in many countries health care is improving. Those people too want to live their life as good as possible and that means that they are going on holiday, having a job or doing voluntary work.

With kind regards,



Maryze Schoneveld van der Linde
On behalf of the working group 'Flying with Ventilation'

Stelios Stylianou of the Muscular Dystrophy Association Cyprus, **Cyprus**
Catherine Dinh – Dubuit of Association Française contre les Myopathies (AFM), **France**
Evald Krog, Muskelsvindfonden, **Denmark**
Ivanka Jovanovic, European Alliance of Neuromuscular Disorders Associations (EAMDA), Muscular Dystrophy Association of Serbia and National Organisation of Persons with Disabilities in Serbia, **Serbia**
Dick Cochijs, Dutch Neuromuscular Disease Association (VSN), **The Netherlands**
Maryze Schoneveld van der Linde, Dutch Neuromuscular Disease Association (VSN), **The Netherlands**

This initiative of the working group 'Flying with Ventilation' is supported by the following organisations:

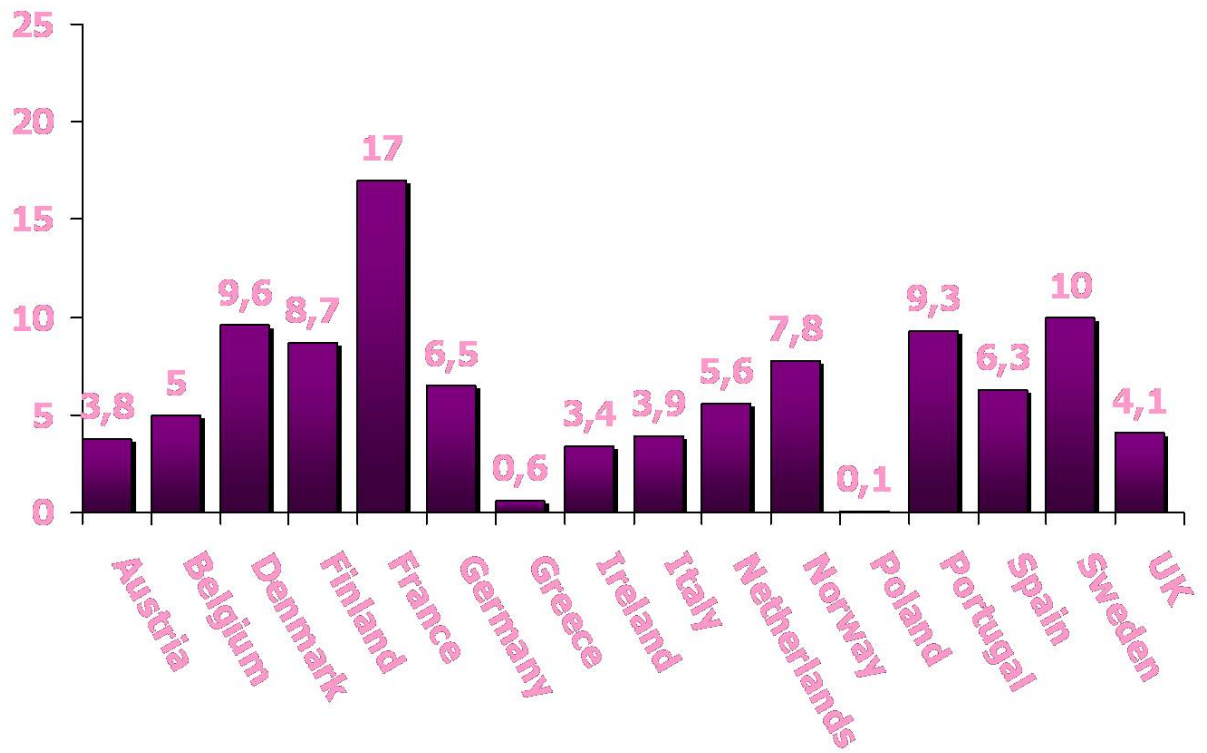
European Alliance of Neuromuscular Disorders Associations (EAMDA) – www.eamda.eu
International Ventilator Users Network (IVUN) - www.ventusers.org
Post-Polio Health International – www.post-polio.org
International Pompe Association (IPA) – www.worldpompe.org
Muscular Dystrophy Campaign - www.muscular-dystrophy.org
United Parent Project Muscular Dystrophy (UPPMD) – www.uppmd.org
Kynnys Ry (The Threshold Association) – www.kynnys.fi
Independent Living Institute (ILI) – www.independentliving.org

Attachments:

Attachment 1: Figure on Prevalence home mechanical ventilation / 100.000 inhabitants
Attachment 2: Letter of support from EAMDA
Attachment 3: Some cases in emails and a letter

Attachment 1

Prevalence home mechanical ventilation / 100.000 inhabitants



Ljubljana, October 21st, 2010

TO:

Maryze Schoneveld van der Linde
Eksterhof 63
7051 WN Varsseveld

The Netherlands

SUBJECT: EAMDA support for initiative "Flying with Ventilation"

Dear Maryze,

Thank you very much for your information about the initiative for "Flying with Ventilation" from October 19th, 2010.

I am glad that I am able to answer positively immediately, as in the letter described difficulties for people with neuromuscular disorders (NMD) who travel with ventilators are very known for several years to a lot of participants of EAMDA activities. It was also a serious discussion about that issue on last EAMDA Annual General Meeting held in Milano (Italy) between 16 and 19 September, 2010.

So, I can express the full support of EAMDA for your initiative and the expected practical measures for solving these unpleasant situations which are terrible for severe disabled people in European countries when they must travel by airplanes and meet different unreasonable praxis, where airplane companies reject or cancel a flight to person with NMD having artificial ventilation / respiration. It is already time these people are equally treated as people with wheelchairs.

I propose Ivanka Jovanovic, vice president of EAMDA to be also included to the working group. She travels often by airplanes and represents National council of Serbian disability organizations on the conferences of EDF.

Best regards with wishes for successful activities,

Boris Sustarsic
President

Maryze

Van: Adolf Ratzka [adolf.ratzka@independentliving.org]
Verzonden: vrijdag 15 oktober 2010 20:03
Aan: 'Maryze'
Onderwerp: RE: Ventilator Use and Flying - Questions to the EU
Bijlagen: Adolf sommarsemester 2007.jpg

Hi Maryze

You raise an important issue. I travel by air nowadays about 10 times a year for work and private purposes and my experiences vary. As I am able to breath on my own for up to about 30 min, if needed, I do not use the ventilator (slim hose in my mouth held between the teeth, see attached picture) while the airport service crew of two persons (code WCHC) gets me from gate to airplane seat. My accompanying personal assistant carries the ventilator cum external battery in a bag. When I am seated and the rest of the passengers enter the plane and keep the cabin crew busy, my assistant puts the bag with the ventilator under my feet. I never tell the airline in advance that I need a ventilator. I tell them only that I need WCHC assistance, but I do have a statement from my doctor with me stating that I enjoy excellent health and need to use a ventilator to continue to enjoy my excellent health. With this policy I have saved myself an enormous amount of hassle. I remember that some 30 years ago when I would sometimes tell the airline in question in advance that I need to carry a ventilator on board I would get into great trouble. The airline would direct me to their medical department which required all kinds of papers and in the end would turn me down anyway.

I would agree with most of the statements you make in your text. But, as I said, if one can board the plane hiding the ventilator most of the hassle is avoided. Once the plane is in the air, they won't throw you out. When I leave the plane upon arrival they do not seem to report and blacklist me. Apparently they realized that a ventilator does not necessarily cause any problems for them.

My current strategy is of course not a solution for everybody. People who need to be constantly hooked up to their equipment face a completely different situation. Therefore it would be good to push for a general solution which does take individual differences into account. I would suggest that people who have sufficient battery power with them and do not need anything from the aircraft or aircraft crew – except for WCHC service - should be able to book a flight and enter the plane with merely a medical statement that certifies their ability to fly. If they need anything more from the airline, such as for example access to the airplane's power outlet or other technical arrangements, they should notify the airline in advance. Eventually, such technical requirements should be integrated into the design of aircrafts in the future.

The most problems I have had were passing security checks when the staff looks at my ventilator and my external batteries with suspicion. I have not been denied a flight because of them but sometimes it felt close. And I haven't been back to the US after 7/11 . I'll go there next spring and am a bit concerned that the terrorist paranoia might affect me.

If you want the perspective of a very frequent traveler with constant use of a ventilator and humidifier (which requires hook-up to the aircraft's power supply) I would suggest you contact my friend Kalle Könkkölä, Helsinki. You can reach him through his work at Threshold (Kynnys ry) <http://www.kynnys.fi/>

All the best with you important work

Adolf Ratzka
Independent Living Institute

From: Maryze [mailto:Maryze@xs4all.nl]
Sent: den 15 oktober 2010 17:30
To: admin@independentliving.org

Kalle Könkkölä 31 oktober om 16:15 [Rapporterer](#)

Dear Maryze

Of course we can support you. I am personally facing this problem very often because my work is very international.

My last problem was with Austrian Airlines. They demanded a certificate for my PLV-100 ventilator, I succeeded to fly with them, but when I asked for the certificate document I provided them with, they could not find in 3 weeks the right document they demanded from me.

I threatened them with publicity and then I got the permission.

I have a certificate from KLM, but it is only valid for that airline.

greetings

Kalle Könkkölä of Kynnys ry

Finland

ps. keep me updated

Maryze

Van: Scheerder, J.J.B. [J.J.B.Scheerder@umcutrecht.nl]
Verzonden: zaterdag 16 oktober 2010 10:09
Aan: Maryze
Onderwerp: RE: vliegen met beademingsapparatuur (ik zou graag input van jullie willen)

Beste Maryze,

Het probleem wat jij omschrijft komt regelmatig voor, vorige week nog een patient die met Arke-Fly ging vliegen naar Egypte die in eerst instantie niet mee mocht vliegen. Uit eindelijk is het toch gelukt om deze patient naar Egypte te laten vliegen, via TEFA heb ik alle benodigde formulieren van de apparatuur gekregen en die naar Arke-Fly gestuurd met een medisch formulier van dr Westermann waar opstond wat voor ziekte en apparatuur deze patient gebruikte.

Het lijkt mij verstandig dat dit ook via de VSN in Baarn loopt, alle patienten met klachten over het vliegen adviseer ik daar contact mee op te nemen.

Met vriendelijke groet,
Jan S

Van: Maryze [mailto:Maryze@xs4all.nl]
Verzonden: vr 15-10-2010 17:05
Aan: Scheerder, J.J.B.
Onderwerp: vliegen met beademingsapparatuur (ik zou graag input van jullie willen)

Air France (Head Office)
45, rue de Paris
95747 Roissy CDG Cedex
France

Air France – Europe
Service Client
TSA 21235
75564 Paris Cedex 12
France

Varsseveld (The Netherlands), 24 June 2010

To Air France Head Office and Air France – Europe,

I fly about ten times a year for my work to countries within Europe, USA and Asia. Due to a neuromuscular disease M. Pompe, I always take my manual wheelchair and respiratory equipment with me. The respiratory equipment (type PLV-100) and dry battery are always taken with me on board, so I can use it during the flight. The equipment can be stored safely under the front seat or in case of the spare respirator in the overhead luggage bin. Since I am flying frequently your partner KLM recommended me to apply for a SAPHIR card. I have used the SAPHIR card several times and my flying experience with Air France so far had been good.

Because of my good experience with Air France I booked a flight to Beirut with your company for May the 17th 2010. The travel agency, Matador Varsseveld, assisted me with the booking. After I returned from another travel I was called by the travel agent that the flight couldn't be booked for me because a part of the flight would be performed by Middle East Airlines. Air France couldn't guarantee me that Middle East Airlines would allow me to use the respiratory equipment on board. Then we booked another flight that would be fully performed by Air France, so there would not be a problem with another airline company. At booking I provided Air France with the Air France SAPHIR number. We were unpleasantly surprised when again my flight was denied. I really didn't understand why this happened as I also travelled without any problem with you to Zagreb (Amsterdam - Paris – Zagreb) in April 2010.

After enquiry why we couldn't fly we were told that the respiratory equipment (two respirators type PLV - 100 and one dry battery) were too heavy in weight. I could only bring them on board when I paid an extra seat. This was never requested to me before by any airline company as I can store the equipment safely away under the seat. But to be able to fly to Beirut to visit a very sick friend who was waiting for me desperately, I decided I would buy an extra seat. Then however I was again told I was not allowed to fly. Now I was told I didn't need to buy an extra seat, but I had to provide Air France with documents that stated it was safe to take the respiratory equipment on board of the plane and also to use it. These documents (the *Declaration of Conformity* by Respirationics for my two respirators (PLV – 100) and the *CAA Design Authority Approval* for the dry battery) were sent to you immediately. It was therefore a big shock to me and also to the travel agent, that one day before departure, I received the message that I definitively couldn't fly with your company. When we, the travel agent and I, asked for

the reason of denial since we did provide you with all information and were willing to buy an extra seat for the equipment, the answer from Air France was: 'We don't need to give you a reason'.

Questions:

1. How is it possible that in the year 2010 I am denied a flight by Air France without giving me any reason? It can't be miscommunication or misunderstanding as there was much and clear communication on this with Air France, Air Trade, the travel agent and me.
2. How is it possible that I flew already several times (last flight was 11 – 14 April 2010) with Air France with satisfaction and without any problem?
3. Why did Air France at different moments in the process set two separate conditions (1. buying an extra seat for the equipment and 2. providing documents that proved safety of equipment to use on board of a plane)?
4. Why did Air France still deny me to fly with them after I fulfilled these conditions?

I request you kindly to inquire why I was denied, why no reason for denial was given, why I was asked to fulfil several conditions at different moments and why I was still denied after I fulfilled all the conditions you required.

I also request you to share the results of this inquiry with me and to let me know if it will be possible to fly with Air France in the future. With your partner KLM this isn't a problem at all.

With kind regards,



Annette Schoneveld
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The Netherlands

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Mob: +31 6 51 27 48 19

Email: maryze@xs4all.nl

Email: maryze@pacesworld.com


Attachments:

- Declaration of Conformity by Respirationics for PLV-100

- CEE Design Authority Approval dry battery

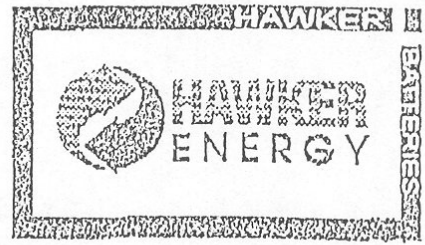


Declaration of Conformity

We, declare under our sole responsibility that the product(s) listed below to which this declaration relates are in conformity with the applicable provisions of Directive 93/42/EEC of 14 June 1993, concerning medical devices.			
Manufacturer: Respironics, Inc. 1001 Murry Ridge Lane Murrysville, PA 15668-8550 USA Tel: 800-345-6443		European Representative: Respironics Deutschland Gewerbestrasse 17 82211 Herrsching, Germany Tel: +49 8152 93060	
Notified Body: TÜV Product Service Number 0123		Conformity is declared to: Annex I Essential Requirements Annex II Full Quality Assurance System	
Product Category:	PLV [®] -100		
Part Number(s) and Brief Description:	35004 Swedish PLV-100 35005 Danish PLV-100 35007 French PLV-100 35008 Italian PLV-100 35010 Dutch PLV-100 35021 Norwegian PLV-100 35022 Spanish PLV-100 35050 English 2-wire PLV-100 35135 English 3-wire PLV-100		
Product Classification:	IIb	Classification Rule:	Rule 9
Harmonized Standards:	EN ISO 13485 EN 60601-1 EN 60601-1-2 EN ISO 14971 EN 794-2		
Date of Issue/Update of Declaration:	See signature date below		
Range of Control Numbers for Product (if applicable):	All		
Approved By: (signature)	 Lou Anne Kinney		September 13, 2006
Title:	Vice President, Quality Assurance and Regulatory Affairs, Sleep and Home Respiratory Group		

Hawker Energy - SBS

Advanced Batteries



CAA Design Authority Approval

Hawker Energy Products Ltd. of Newport, Gwent, Great Britain is fully certificated under the AIR NAVIGATION ORDER as a design authority Type A1.

Registration Number: DAI/3071/50
Issued by: Civil Aviation Authority (UK)

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Or one of our international representatives