

**ISSUES AROUND THE NEED FOR AN EQUITABLE
AND COMPREHENSIVE PROGRAM TO ADDRESS
VENTILATION AND/OR OTHER ASSISTED
BREATHING RELATED REQUIREMENTS FOR
CERTAIN PERSONS WITH DISABILITIES IN
NEW BRUNSWICK**

PREPARED BY

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RATIONALE

The United Nations Convention on the Rights of Persons with Disabilities states in parts of the Preamble that:

“e) Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis.”

“h) Recognizing also that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.”

“i) Recognizing further the diversity of persons with disabilities.”

“j) Recognizing the need to promote and protect the human rights of all persons with disabilities including those who require more intensive support.”

“n) Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.”

Canada is one of the leading countries who helped craft this recent U.N. Convention on the Rights of Persons with Disabilities.

We strongly believe that persons who need ventilation supports in order to be able to breathe and thus to live should be protected.

We need to communicate more effectively so that all of the stakeholders and decision makers truly understand that they have a legal and moral obligation to ensure that ventilation services are provided to meet the needs of such persons not only to preserve life but also to offer significant improvements to the quality of life for appropriate candidates.

Such interventions can certainly add to the sense of dignity and self control for those patients who wish to have access to ventilation but will have the potential for independence and improved quality of life if they are able to live in their community and not be restricted to life on a hospital ward.

INTRODUCTION

Over the years the Premier's Council on the Status of Disabled Persons has been involved in some situations where a person would be required to have a ventilator or other device to assist them in breathing due to their disability.

The number of such cases throughout the province is relatively small and there was never really a clear or consistent process to address these situations. Each person and family affected seemed to have to start all over again when seeking information, access to equipment, funding for supports related to caregiving and supplies, and even where such a person would be able to live if not with their own family.

According to information provided by the equipment suppliers, we are aware of the following numbers of persons who are currently trached and ventilated in New Brunswick and living in the community:

- Moncton area: 5 cases
- Fredericton area: 4 cases
- Bathurst area: 3 cases

(Note that there are 19 ALS cases in the Bathurst region on BiPAP machines and some of these people could require invasive ventilator later.)

There may also be a small number of ventilated clients still living on extended wards of hospitals due to lack of arrangements for community supports. **We are currently aware of three patients living at the Saint John Regional Hospital who are ready to be discharged whenever the necessary housing and support services are arranged in the community.** These ventilator users may be able to share support services and accessible housing at lower overall cost if they are willing to live together. They have been waiting a long time to obtain the necessary decisions and funding to allow the appropriate discharge process to be implemented. However, even those clients now living in their communities generally have expressed dissatisfaction with the discharge planning and how long it took to get out of the hospital after being ventilated.

Organizations like Muscular Dystrophy Canada, the Canadian Paraplegic Association, and the Amyotrophic Lateral Sclerosis Society and others have struggled with these issues for their clients along with their medical and

rehabilitation support teams and of course their families.

The Premier's Council on the Status of Disabled Persons agreed to look into these concerns. Information has been gathered from stakeholders and other sources and we have prepared this discussion paper with specific recommendations to address ventilator and other related assisted breathing issues in a more equitable and systematic way in New Brunswick.

We have shared this discussion paper with a number of stakeholders for their input and support and feel that we have enough information at this point to request more formal discussions with the government of New Brunswick. We would like to receive some feedback in particular from the departments of health and the Department of family community services on how to better integrate the available services to meet the needs of such individuals. Furthermore we will also need to ensure that medical professionals and rehabilitation professionals are given an opportunity for input to this process as well as to provide a strategy for better education to the medical and rehabilitation community about the options available to address future ventilation of clients with significant respiratory difficulties to include both invasive and non-invasive ventilation intervention.

The patients and their families need to be informed of all of the options available to address their needs and to be supported in a timely and effective manner so that these individuals are enabled to get on with their lives in the community in a safe and dignified manner. The Premier's Council on the status of disabled persons will be happy to assist in further joint discussions on these issues in the hope of achieving concrete outcomes in a reasonable period of time. We also intend to circulate this discussion paper to other interested parties in the hope of receiving further ideas and to build consensus for timely action and equitable access to the required ventilation related supports for such individuals.

CONSULTATION AND INFORMATION GATHERING

On October 3, 2006 the first formal consultation meeting was held in Fredericton involving the following interested groups:

- Premier's Council on the Status of Disabled Persons
- Muscular Dystrophy Canada – Atlantic Region
- Amyotrophic Lateral Sclerosis Society of New Brunswick
- Easter Seals New Brunswick
- Canadian Paraplegic Association (N.B.) Inc.
- Stan Cassidy Centre for Rehabilitation

The participants at this meeting all agreed with the need to improve the current situation to reduce the financial and emotional stress being faced by such individuals in New Brunswick. Further meetings, research and consultations have since been undertaken resulting in the preparation of this report.

Coincidentally, the Summer 2006 issue of the *Connections* national magazine from Muscular Dystrophy Canada had several articles related to this topic. **(See Appendixes “A”, “B”, and “C”).**

A roundtable discussion raised points around the current situation in New Brunswick and included such specific concerns as:

- We must ensure that doctors and other health professionals were made aware of the option of ventilator use and other methods now available to assist breathing for some patients with progressive neuromuscular disorders, etc...
- The client's definition and wishes about quality of life and the client's right to choose based on correct information must take precedence over the personal attitudes, assumptions and philosophies of the attending physician.
- The cost of ventilators and other types of equipment used to provide respiratory assistance is expensive and are not automatically covered by either public programs or private insurance for those who have insurance. **(See Appendix “D” for some examples of equipment costs and adaptations to wheelchairs to carry the equipment. We have received**

other specific pricing information from suppliers which we could provide to government when the time is appropriate but we have not included the information with this paper to protect competitors who may be bidding with each other to supply such equipment and services through programs funded by government.)

- There are some additional costs for supplies and maintenance depending on the type of options being used.
- Caregivers need to be properly trained to safely manage the equipment and provide emergency intervention in cases of equipment failure, power interruptions or other crisis management to ensure that the client is protected.
- Obtaining adequate funding to pay for adequate levels of support care hours in the home and community has been an on-going issue for such clients. Family caregivers also need some periodic relief for the hours of care that they personally provide as well as getting adequate funds to pay for appropriate external caregivers.
- Links are required with local community emergency response services to be aware of such residents in the event of power failures or interruption in breathing requiring prompt attention from ambulance or other emergency measures personnel.
- Who should pay for electric power backup for generators or for backup ventilators?
- Some clients had been held in extended care beds at hospitals for long periods due to problems in arranging community supports and finding an appropriate place to live. We have confirmed from the appropriate officials that even nursing homes do not accept ventilator dependent residents.
- Presentations made to successive governments and to officials within the government bureaucracy have not yet led to a resolution of these issues. It is hoped by working together, the different stakeholder groups who deal with such clients would have greater potential for improved

outcomes with government.

- Support for clients to enable them to breathe should be considered an essential service and be covered by public programs for those unable to pay related costs by themselves. The alternative for such persons is literally death when they cannot adequately breathe for themselves. Furthermore, using the devices for breathing assistance saves energy and effort better utilized for the person's enjoyment of an enhanced quality of life.
- There was some interest expressed in exploring ways to recycle the use of such equipment if still appropriate so that in some cases investments in equipment can be made for purchases and then recycling versus leasing or renting. Of course we must be respectful of technology changes and ensuring correct matches to clients. There may even be room for sharing equipment within the Atlantic Provinces to achieve economies of scale or keeping prices down by volume purchases. This has been implemented in other jurisdictions such as Ontario.
- If there must be a means test for contribution, we need to review the process to look at not only income but also legitimate household expenses. However, we want to ensure that private health insurance plans are not able to off load costs to public programs. We also need to address the issue of personal responsibility for means testing with an adult living at home with their parents' income now being considered as well. Should parents of such individuals be expected to use all of their retirement savings and/or other income to pay for equipment and other support costs for their son or daughter to receive medically necessary ventilator services or should we only look at the income of the adult patients?
- We need to develop a list of what types of assisted breathing options and related equipment that will be covered in future publicly supported programs, i.e.: ventilator dependent only with a tracheotomy; the non-invasive mouthpiece ventilation (NIMV) (**Please see Appendix "B"**); Cough Assist machines; Pulse Oximeters; BiPAP machines or C-PAPs for use during the night to supplement breathing while sleeping; and other emerging treatments such as the diaphragm pacing system being

implanted through surgery at the Vancouver General Hospital; etc...?

- How do we compare to other provinces on programs to support ventilator dependent clients? Information shared at the October meeting seemed to indicate Newfoundland and Labrador has some support program advantages but Nova Scotia and Prince Edward Island are not better than New Brunswick. We need to get more information on the differences in services mentioned for Newfoundland.
- There might be interest in organizing a stakeholder conference around ventilator issues for either New Brunswick or possibly the Atlantic region. We do have a summary report on a **Forum on Ventilator Assisted Living: Strategies for Living Well** held in September of 2006 in Edmonton, Alberta that discussed issues similar to our situation here in New Brunswick.
- There is obviously a need to include medical and respiratory professionals in a structured educational campaign around these ventilation issues to ensure that they are knowledgeable about all of the treatment options and how to help their patients access the appropriate support services that will be needed when they return to the community after treatment. Medical practitioners, rehabilitation professionals, funding sources, families and the patients themselves must have all of the current and appropriate information necessary to make the best choices for the persons affected.
- **Other issues?**

NEXT STEPS

1. We will circulate this discussion paper to any other interested stakeholders that we can identify and invite them to share any other ideas or data that should be reviewed as part of the information sharing process.
2. We will request **initial feedback** from key officials within the Department of Health and from the Department of Family and Community Services to include their specific recommendations to offer solutions to these issues. We would ask for this initial feedback to be received **by March 16, 2007** through the Premier's Council on the Status of Disabled Persons.
3. The Premier's Council on the Status of Disabled Persons will be meeting March 24th and 25th, 2007 and will review these issues in the initial feedback from government and others. The Premier's Council will **prepare a formal document with a final list of specific recommendations for consideration by government to be submitted before the end of April.**
4. The Premier's Council on the Status of Disabled Persons will hold another larger **meeting with stakeholders before the end of June 2007** to review the responses provided by government to the specific list of recommendations.
5. Interested stakeholders will be encouraged to assist the Premier's Council in the follow-up activities to create support for the implementation of options to improve the situation in New Brunswick.
i.e.: - letters of support for the recommendations
- media contacts
- lobbying with the government
- seeking support from medical and other health professionals
- etc...

RECOMMENDATIONS

1. An ongoing structured educational campaign should be implemented to ensure that all appropriate medical and rehabilitation professionals are made aware of all of the current options possible to address ventilation issues for their clients and to be supportive when clients make informed choices. This should include participation of the New Brunswick Medical Society and the various other professional associations representing respiratory therapists, occupational therapists, physiotherapists, etc.
2. Patients, families, and other caregivers need to have consistent access to quality education and follow-up supports to ensure that they are able to confidently and safely manage their ventilation care issues in their home and community environment.
3. Third-party caregivers need to be properly trained to safely manage the equipment and provide sanitary and appropriate support to the client using ventilation intervention technology. Funding sources used to pay for the cost of such higher skilled caregivers who are assuming more serious levels of responsibility must be aware of the need to adequately compensate such skilled caregivers to ensure success in recruitment and retention of such workers.
4. The cost of ventilators should be specifically covered by Medicare. Other types of required essential ventilation equipment should be covered by a publicly funded program either through Medicare and/or through the Department of Family and Community Services. Such essential equipment should be considered “a basic need” for survival and be eligible for automatic government financial assistance. Government could work with equipment suppliers using bulk purchasing and the tendering process to ensure the lowest possible fair costs to the system.
5. The provincial government should also move to provide some of the ventilation related equipment and technology when possible through a shared equipment recycling program in order to lower ongoing costs for such items. Consultations could be explored with the other Atlantic Provinces to see if economies of scales could be utilized with some kind of joint ventilation equipment recycling initiative. However we need to see

something done on this matter here in our own province one way or the other. Of course recycled equipment must be appropriate and still functional for sure with another person and the technology must be kept current.

6. Patients and families should have access to financial supports when needed for the cost of supplies and required maintenance for the use of ventilation technology and devices at home or where ever they live in the community outside of the hospital or rehabilitation center. When means tests are required, they should be completed in a timely and fair manner.
7. Discharge planning for patients with ventilation issues must automatically include arrangements to prepare for necessary emergency intervention in the case of equipment failure, power interruptions or other situations that may pose risks to the client in their home environment. Local community emergency services should be made aware when a ventilator dependent person is living at a specific location in their area so they will be prepared if an intervention is necessary.
8. Government needs to explore specific housing options for ventilator dependent individuals who would be able to live in the community outside of the hospital environment provided they have the necessary equipment and support services. Not all such patients will be able to return to the family home due to lack of physical accessibility and/or the health status or availability of parents or siblings to provide required ongoing support services and emergency backup. Small community residences may be one option if several persons with such special needs could live together to share services and control costs. Remember that we are not talking about large numbers of such ventilator dependent individuals in small province. We would also especially wish to ensure that families are given adequate support when they desire to have their family member returned to live in the family residence. They would however likely need assistance with renovations to their homes and certainly with support care and respite care.
9. Government should make contact with the other provincial jurisdictions across Canada to determine what supports and what options are currently offered in their programs to address the needs of persons using ventilation due to their disability.

10. We may have other suggestions to make in the future such as the need to develop a provincial Centre of Excellence on Ventilator Issues to serve as a resource to both patients and professionals in New Brunswick. This will require further discussions with the stakeholders.

APPENDIX A

“How Steven – and his parents – began to breathe again” by Donalda Jones

On January 4, 2005, when he was 20 years old, my son Steven began to breathe – better than he had been breathing for years – with the help of a tracheostomy and a ventilator. Steven had himself made the decision to be ventilated, and had been carefully prepared, so that he knew what he was doing.

Steven had been diagnosed with Duchenne muscular dystrophy when he was five years old. At first it was not expected that he would live long enough for ventilation to become an issue. But Steven lived, and in time the questions around breathing moved to front and centre. So it became our job as parents to give Steven all the information he would need to help him make his own choices about ventilation and his body. For a couple of years we read, talked, and educated ourselves on the issue of ventilation. I travelled to Toronto to attend a conference specifically on respiratory issues and ventilation, one that brought together specialists in the field and young men living with ventilators, as well as a range of other experts. I thought that my husband Dale and I were as well prepared as our son for this new stage in Steven’s life.

What we were not prepared for, however, was the startling *lack* of awareness of ventilation issues that we found in the medical community, beginning the day after Steven’s surgery.

Some of the things I need to say may make you uncomfortable, or you might just plain not want to hear them. Believe me, I have been there. But shared awareness really helps. Let me tell you how the story unfolded.

Steven went into a wheelchair at age nine. During his childhood and early teens, there was no sleep clinic for children in our province. We had to go out of province for help. During those years it was recommended that Steven use a bi-pap machine, which is considered to be a non-invasive form of ventilation. Steven tried it for a year. He knew it was the last line of defence prior to ventilation, and he knew all the reasons he should stick with it. But he could not ever get comfortable using bi-pap.

When Steven turned 18, he could access an adult sleep clinic and a doctor who

specializes in respiratory disease. We began to understand and pay attention to signs of respiratory failure. Steven had headaches, leg cramps, memory loss, weight loss, and nightmares; we learned how they were connected with the inadequacy of his breathing. The doctor monitored his blood gases and oxygen levels.

By the time Steven turned 19, he could no longer cough out mucus plugs. Trips to emergency to clear his airway entered the picture. My husband and I made the agonizing decision for Steven to move to a care facility – something I had said I would never agree to. It was the hardest decision we ever made, but we knew the time was now for us to get back to being Steven’s parents rather than his caregivers, mired in survival mode. Steven moved into a facility in our own city on October 23, 2004.

We soon learned that most staff in the institution were not up to speed on respiratory issues for people with neuromuscular disorders. When Steven’s oxygen levels would drop at night (causing his buzzer to go off), they would rush to give him oxygen – even when Steven protested. He knew that people with neuromuscular disorders should not be given long-term oxygen unless they have a way of getting rid of it, such as ventilation. The more oxygen you give, the more carbon dioxide builds up, therefore the more harm.

Dale and I decided that a conference with Steven’s respiratory specialist and the rest of the long-term care team was needed. It was swiftly decided that no more oxygen should be given. The time had come for Steven to have a tracheostomy and look at some hours of ventilation. Steven agreed, and was promptly referred to an eye, ear and throat surgeon.

The doctors’ hope was that a tracheostomy would shorten the breathing passage enough that Steven might not have to be ventilated. If that did not work out, the second hope was that the ventilator would be needed only at night. The third option was that Steven would stay on the ventilator 24/7. The surgeon made sure that Steven understood this range of outcomes and that he did not feel pressured.

The surgery on January 4 went well. After it was done, Steven was moved into the Surgical Intensive Care Unit (SICU).

It was then that we really ran into trouble.

We had not realized that SICU was “a closed unit”, or that our respiratory specialist would not be able to visit and follow Steven until he was out of SICU. Nor had our doctor briefed the SICU staff before Steven’s arrival following his surgery. They thought that Steven was like any other post-surgery patient, and their one and only goal was to wean him from the ventilator. Every time they tried to do that, up went Steven’s carbon dioxide levels. We argued and told them of the danger, but they neither listened nor believed us. Instead, they began to treat us as “bad parents” who would “spoil” Steven by leaving him on a ventilator instead of urging him to try harder to breathe on his own. They stopped talking to us about the daily details of Steven’s care. A kind of ice wall went up around the staff.

As for Steven, he was beginning to be terrified. With his tracheotomy so new, the still could not speak. He became fearful that if we left him alone, the staff would take away the ventilator, which was allowing him to get a good breath at last, after years of painfully impaired breathing.

And one night Steven’s fear came true. The medical team took it upon themselves to wean him from the machine during the night, when he was all alone – and to do it not just for a short time, but for twelve hours. By the time we got back to the hospital in the morning, Steven was dying. I could not believe the staff could be so cruel. It was brutally clear that they did not understand the processes of neuromuscular disease.

Ten days after surgery Steven stated that he wanted to remain on the ventilator 24/7. We supported him in that decision, and we made that clear to the staff. It was a stand-off: They thought we were ignorant and emotional, we thought they were dead wrong.

Then SICU called for a meeting of the medical team – to try to convince us, we suspected, that Steven’s decision to stay ventilated 24/7 was a mistake. But on the Monday of the week of that meeting, a different internist (because of a routine rotation) took over in the unit. This medical specialist was present at the meeting, and her first words were: “I see no reason why this young man should come off the ventilator.”

Her knowledge made all the difference. That afternoon Steven was transferred to the ventilator ward, where there were three other ventilator patients and our doctor could freely visit and direct care. The road to recovery was allowed to start.

Steven was in the hospital for 105 days. There were other battles, but we fought them smarter. I began to phone Judy Spink of Muscular Dystrophy/Atlantic Canada, whenever there was a major problem. From thousands of miles away, she held our hands and gave good advice. Often the medical team did not know how to account for the muscular dystrophy factor in Steven's healing and in the time frame for his recovery. Judy's experience allowed her to factor everything in. Together, we made it through.

Now it is more than a year later, and Steven is pink, healthy, able to sleep, and (best of all) happy. Our lives have changed, but we are all grateful for the option of ventilation – an option we had once thought we could never accept.

If you are considering this option with someone in your own family, know that you should go into this journey prepared and supported. Some of the facts on this difficult road are very new to the medical profession, and not everyone has had time to assimilate them. You need a persistent specialist. You need contact with other families. You need a support team of people who can stay close to your patient during the long stint in hospital. This support is needed for the parents as well as for other children in the family. You need a plan – a “path”, like the one we were helped to create almost two years prior to Steven's surgery. You need contact people who can help ordinary hospital staff access up-to-date awareness of the unique factors at work in any patient with neuromuscular disorders.

The support I received makes me eager to support others on this path. If I can be a resource to anyone, you can always reach me through Muscular Dystrophy Canada or by e-mail at: donj@accesscomm.ca.

APPENDIX B

“Is there an alternative to a tracheostomy?” by John Brock

Are you nodding off during the day? Do you wake up frequently during the night? Have lost your “get up and go”? Has your appetite got up and gone? Is it becoming more difficult to swallow? Are you losing weight?

These are the signs that you may not be getting enough oxygen and your body is expending too much valuable energy trying to keep itself properly ventilated. Perhaps you are already using a BiPAP machine. However, at some point a BiPAP machine won't be enough and you will require daytime ventilation as well. At this point you are typically told that you must have a tracheostomy (along with a G-tube if your weight is too low). But is there another option? Well, yes there is! It's called non-invasion mouthpiece ventilation (NIMV). With NIMV you take breaths of air from a ventilator through a mouthpiece (whenever you feel you need it).

If you are on NIMV does that mean you will never need a trach? There is no guarantee that you will never need a trach but you may be able to avoid a trach for many years. Some persons on NIMV have lived their entire life without a trach. A tracheostomy is a stressful procedure for you and your family and places a significant additional work load on caregivers who are already burdened both physically and emotionally.

So, should you opt for NIMV instead of a trach? That's a personal decision for you to make in consultation with doctors. But you owe it to yourself to check it out!

My son David is 24 years old and has Duchenne muscular dystrophy. In June of 2005, despite being on a BiPAP ventilator at night, David's CO₂ levels had risen to the point where he was advised to undergo an immediate tracheostomy (and have a G-tube inserted because his weight had fallen too low.) Instead David went to the Rehabilitation Centre of the Ottawa Hospital (the only clinic in Ontario, that I am aware of, which offers NIMV) and went on NIMV. Since then David has improved remarkably under the care of Dr. Doug McKim and Carol Leblanc, RRT at the Respiratory Rehabilitation Centre. He no longer requires a tracheostomy! As well, because of NIMV, David has more energy

available to eat and his appetite has returned. In fact David has gained six pounds and no longer requires a G-tube!

For more information please go to the Rehabilitation Centre's educational web site: www.rehab.on.ca/irrd/education and click on "Respiratory Protocols for SCI and Neuromuscular Diseases".

For a parent's perspective, please contact me:

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(pleaser use "NIMV" in the subject line)

APPENDIX C

“A Word from Dr. McKim” by Dr. Douglas A. McKim

The fine young man described in John Brock’s article is fortunate that everything has worked out well for him and for his family. He has been able to avoid the recommended tracheostomy and has clinically improved both in gas exchange and in other measures of quality of life: appetite, sleep, energy.

There are, however, a number of requirements which can predict success with mouthpiece ventilation, and many circumstances under which it may not be possible and a tracheostomy would still be required.

Good candidates for non-invasive mouthpiece ventilation (NIMV) must have sufficient strength and coordination of their bulbar muscles (i.e., be able to speak, swallow and protect their airway) to be able to safely use a mouthpiece to sustain ventilation for life support. We are very fortunate in Ontario to have the excellent services of the Ventilator Equipment Pool through which the Ministry of Health and Long-Term Care provides a lifetime loan of up to two mechanical ventilators for home use. This allows one ventilator to be chair-mounted and one to be at the bedside for those who require over 16 hours of daily support. Chair-mounting enables the provision of mouthpiece ventilation.

Patients who have already undertaken a program of regular lung volume recruitment (LVR/”breath-stacking”) are also in a better position to accommodate to mouthpiece ventilation due to their familiarity with the technique. The compliance (or distensibility) of their lungs and chest is also a factor, and this factor may have been improved by a lung volume recruitment regime.

It helps to be a bit of a risk-taker if you plan to try mouthpiece ventilation, because there is the perception that this form of ventilation carries some enhanced risk. It is true that there is a sense of security to the firm attachment of a tracheostomy tube and tubing but this may be more than offset by the increased care requirements and tracheostomy-related complications. Patients must be capable of understanding these issues and making an informed collaborative decision.

Ventilation at night is provided by a non-invasive mask. Follow up is required

including regular monitoring of overnight oxygen levels in order to ensure adequate ventilation. It must also be accompanied by airway clearance techniques which are necessary to the success of long term non-invasive ventilation.

This is not a new approach. Dr. John Bach of New Jersey is its greatest advocate, but mouthpiece ventilation has been practiced in some form since the polio epidemics of the 1940s. The option should at least be offered as a choice to be discussed, even if the appraisal that must be made finally concludes that mouthpiece ventilation would not be a good choice for the candidate in question.

Doug McKim

*Douglas a McKim MD, FRCPC, FCCP, D, ABSM
Medical Director, Respiratory Rehabilitation Services
Associate Professor, Department of Medicine,
University of Ottawa.*

APPENDIX D

Examples of costs:

- a) Ventilator = \$12,000 - \$15,000 to purchase machine
- b) Ventilator – Rental = \$1,700 per month
- c) Humidifier – Rental = \$50 per month
- d) Cough Assist Machine = \$7000 approximately
- e) Lung Volume Recruitment Kit - \$50
- f) Peak Flow Meter = \$30
- g) Pulse Oximeter = to be confirmed
- h) Attendant care costs could be up to \$6,000 per month depending on the number of hours required that are not provided through the family for free.
- i) Some examples of costs to adapt wheelchairs to carry the ventilator with the client provided by SCCR:
 - batteries cost anywhere from \$250-\$500
 - trays for vents start approximately at \$1,200
 - one client costs was \$520 including battery, voltage reducer and labour
 - a completed tray assembly for a client with TRXO 142 cost \$1,607 in 2001
 - vent tray for a Quickie 626 wheelchair cost \$1,695
 - modifications to rear of wheelchair to accommodate a new vent was \$339
 - modify power chair to use Bi-PAP cost \$716 so far in one recent case

APPENDIX E

Ventilation Stakeholders Advisory Committee

Randy Dickinson – Executive Director
Premier’s Council on the Status of Disabled Persons

Dr. Colleen O’Connell – Psychiatrist
Stan Cassidy Centre for Rehabilitation

Judy Spink – Director of Patient Services – Atlantic Region
Muscular Dystrophy Canada

Janika Smit – Patient Services Advocate
ALS Society – New Brunswick

Kari Clark – Patient Services Advocate
ALS Society – New Brunswick

Julia Latham – Executive Director
Easter Seals New Brunswick

Krista Porter – Occupational Therapy
Stan Cassidy Centre for Rehabilitation

Haley Flaro – Executive Director
Canadian Paraplegic Association (N.B.) Inc.

Denise Mazerolle – Social Work Department
Stan Cassidy Centre for Rehabilitation

Allen Parlee – Parent
Premier’s Council on the Status of Disabled Persons

Kelly Comer – Physiotherapy
Stan Cassidy Centre for Rehabilitation

Karen Grotterod-Milczarek – Neuromuscular Clinic Coordinator
Stan Cassidy Centre for Rehabilitation

Sylvie Hebert – Social Work
Stan Cassidy Centre for Rehabilitation

Dr. Graham Bishop – Respiriologist
Saint John

Dr. Wendy Stewart – Pediatric Neurologist
Saint John

Linda Lawson – Respiratory Therapist
Quality Respiratory Care Company – Fredericton

Note: We have also shared this information with a number of other physicians, respiratory therapists, equipment suppliers and other interested stakeholders. It was not possible to have all of these contacts to attend the Ventilation Stakeholders Advisory Committee. We will continue to share further information as it becomes available with any interested stakeholders.