BCHPCA FORUM | 2014

SATURDAY MORNING SESSION MAY 10, 2014 9:30-10:30

Political Conversations with public leaders and persons of influence to build relationships and partnerships to advance responsive quality care in British Columbia.

KEYNOTE

Influencing People of Influence

MARY COLLINS: Director of the Secretariat, BC Health Living Alliance; Chair, Chronic Disease Prevention Alliance of Canada; Former Minister of Health, Government of Canada

Mary Collins is the Director of the Secretariat of the BC Healthy Living Alliance which promotes collaborative action to reduce chronic disease and health inequities. She is also Chair of the Chronic Disease Prevention Alliance of Canada. Throughout her career, Mary has been involved in health policy and practice, locally, nationally and internationally. She served as a Member of Parliament and as Minister of Health among numerous other portfolios. She also served with the World Health Organization in Russia. Mary is a graduate of Queen's University and has been awarded Honorary Doctor of Laws degrees from Royal Roads Military College and Royal Roads University.

LORRAINE GERARD, BCHPCA Executive Director: We're ready to move into content for today. Today we're going to start with Political Conversations. Those would be where we're using "political" in a bit of a broad term to talk about public leaders, people of influence, how to build relationships and partnerships to advance responsive quality care in BC. It amazes me that how often I'm talking to someone and you can talk about the big picture of hospice palliative care across the province and what happens is, the conversation ends up talking about somebody's mother, somebody's spouse, somebody's child. I keep reminding myself – I'm going to be speaking to a group of very influential people – the important piece for us is to talk about the fact that it's all so relevant to every one of us.

You probably know that I used to work with the Kidney Foundation before I came to the BCHPA and many of the times that I would present, I would say, now in a group like this, "If you're comfortable to let me know, does anybody here have compromised kidney function?" You might get one or two people putting up their hand. When I first did that, one of my staff said, "Well, what if nobody puts up their hand? You've got nothing to say?" I said, "No, no. That's just question number one."

I'd say, "How about if anyone has diabetes?" In a room this size, you're going to get some people. "And how many of you might have high bold pressure?" Now you've got a third of the room with their hands in the air. Now we've got something to talk about. Kidney disease has a relatively small incident rate from the greater population. But if we go back to Sharon Carstairs' quote from yesterday "You're all going to die ... now we're going to talk about how you want to do it", it's not the same about dying. We're all going to be in there, whether we're people of influence or we're people working in hospice palliative care or you're everybody else.

So to start our public conversations, our political conversations, I'd like to introduce Mary Collins. Mary is the Director of the Secretariat for the Healthy Living Alliance of BC, the Chair of the Chronic Disease Prevention Alliance of Canada, former Minister of Health with the Canadian Government and a member of the Sovereign Order of St. John. Mary ... [applause]

MARY COLLINS: Thank you Lorraine. It's really great to be back here. I'm looking around the room and I'm thinking over the last few years, I was for a period of time the liaison between the [Sovereign] Order of St. John and the Association. I came to a number of board meetings during those years –and they were some challenging years as some of you may recall – and to

some of the conferences and conventions. It's really heartening to know how well the association is doing now and just to look around the room and see how all of you are working so hard throughout the province to advance issues around hospice and palliative care.

I was delighted just talking to Ross [Sharpe, Sovereign Order of St. John] this morning to hear about the presentation of our award yesterday [at the BCHPCA Awards]. I was part of the review committee and we were just so impressed with the quality of the submissions and the great work that you are doing. Can I just ask for a show of hands from those of you who are recipients of our six awards? Great. Good. I've already been hearing some of the stories and particularly the story around Camp Kerry. Who's the Camp Kerry rep here? They're not here today? Oh what a pity because they're wonderful stories. I'm going to come back to that because stories are so important in advancing your issues at a provincial wide basis.

Congratulations to all of you, and also for the report [BCHPCA Hospice and Palliative Care Services Study]. I just had a chance to kind of briefly go look at some of the highlights when I arrived this morning. I think it's going to be a very important part of how you can advance your case, because there's some wonderful information there about not only the quantity of the work that is going on throughout the province in hospice and palliative care but the quality and contribution you're making in volunteer time and the financial implications of that. That's really going to be helpful.

I also want to acknowledge and recognize Dr. Margaret MacDiarmid [former BC Minister of Health]. I know Margaret is going to be speaking a little bit later but it's so great to see you here because talking about influencing people of influence, quite honestly Margaret, you were the big champion around hospice and palliative care when you were serving as Minister of Health and you did so much to advance that case and I know we're all so grateful to you. [applause]

In fact looking at who is coming to this meeting today, well you've got people of influence coming, After I [talk], you've got Margaret and George Abbott [another former BC Minister of Health] and other folks. That's a very important part of moving your case ahead.

I was going to use a PowerPoint and I've decided not to because it's supposed to be a conversation and I'd like to just sort of engage, tell you a few of my thoughts about moving ahead in terms of influencing people of influence to advance your advocacy case. But then also hear from you. Let me just start with a couple of thoughts.

First of all, the important things as you think about moving ahead on your advocacy agenda are to build your case. I think you've got all the pieces of that around, whether the survey and at a local level, there's the story of what you're doing. But you have to have a really good case for what it is that you're trying to advance. As I look at the priorities of the Association, which I'm assuming reflect the priorities of the individual organizations as well, it is to ensure equitable and access to quality hospice and palliative care. Although it's indicated in the survey, there's a lot more activity around providing palliative care support. There's still a big gap in terms of providing the actual hospice spaces throughout this province. That's obviously a big area.

Then obviously to promote advance planning and I know another of your goals is to actually have a registry that's a very specific project which when I think about it doesn't seem all that difficult to do. We have registries of, all kinds of registries now and with the technology you think that would be something you really could do. But you need to build that case.

Then you need to tell the stories. If there's anything has an impact, whether it's on the general public or whether it's politicians, it's the stories. The statistics are great – the bureaucrats like the statistics – but the politicians like the stories

because after all, they're representing people. I'm sure you've got hundreds of stories because you know whether its stories like from Camp Kerry – the impact that that's had on young people – or in the hospice how you've been able to help families and individuals through end of life in a dignified and supportive manner. Those are wonderful stories.

I always compare the impact that children have. When you look at Children's Hospital, how amazing they are at being able to fundraise and the wonderful stories that they are able to convey. Everybody kind of grabs on to stories around children. But you've got stories about grandmas and grandpas and, but that next generation down, to help them be aware that they want to be able to help their grandmas and grandpas, their mothers and fathers to have a dignified and supportive end of life. There's some wonderful stories that I know you can tell.

I just wanted to relay one story. When I was an elected Member of Parliament – it was before I was a Minister actually at the federal level – I was thinking about the influence that one person can have. One day at my constituency office – and I represented the North Shore and up the Whistler, Squamish, Pemberton area. This woman came to my office and she had recently had a child and the child had been ill and had to stay in hospital for, it was well over six months. So she had gone back to work in the interim. But the way that the then maternity benefits were organized under Employment Insurance did not allow her to postpone getting the benefit. She had to take it and she couldn't take it at the time that she had the child. She was really losing out on a good six months and she felt that was unfair. I thought it was unfair too. It seemed like a pretty logical thing that you should be able to get your maternity benefits at the time you have the child, and you have to care for the child in your own home.

I was able to take that story back to my colleagues in Ottawa and with our BC caucus and the then Minister of Employment, and actually put forward a private member's bill. Before the private member's bill even got debated, I was able to persuade the then Minister to change the Act so that in fact you now can begin your maternity benefits at the time that you are with your child. I always think of that. That was one person and the story that influenced ... and I, around fairness and access. Never underestimate that power of individuals to tell their stories and to be able to change policies and change practice as well. Telling the stories is a really important part of any kind of advocacy campaign that you want to go on with.

I think the third thing is to really think hard about how you align your asks with the priorities of those to whom you are asking. It may be in many cases you're working at the local level and you're talking to local governments or you're talking to your health authority. You have to be pretty knowledgeable about what their priorities are, what their views are and do your homework and understand where they're coming from when you go and talk to them. It maybe that you're taking an issue that they're not familiar with or they haven't supported in the past. You have to find some of those hot button sensitive points that you can bring them around.

Then of course particularly when you're dealing either at a provincial or a federal level with governments, it's so important to be able to show how your ask aligns with their broader agenda. This can be quite challenging because ordinarily in advocacy, you not only talk to whatever party will be in power in government, but you also talk to the Opposition. Because you never know, from time to time, who's going to be in power and also Opposition parties can be very effective in bringing issues to the table as well. You have to be careful you don't have two different stories. But you can find ways of aligning with whichever party, the Green Party or the NDP or the Liberals – whomever – the Conservatives. Find ways to speak to their priorities and speak to their issues as well.

Then of course you need a really good implementation plan and most, if you get to the point where you're actually asking for money, you're asking for legislative change, people want to know "Okay, what are you actually going to do? How are you

going to do it?" It's all very well to come and say, "We want, we need $5 million for improving hospice care and building new hospices." But you have to be quite diligent about what you would actually do, how you would do it, and what that money would be used for. Sometimes that can be challenging.

If you look at a provincial level organization, there will be lots of I'm sure competing demands among your own members if you're … what should your priorities be, where should there be new facilities or new support. Even among your priorities, should more support be going to building infrastructure and actual hospice facilities or to services for those who need the palliative care and hospice support? You have to come to agreement among yourselves either both at a local level and at a provincial level about what those priorities would be. Make sure that you have the case.

In the old days, the way that you kind of did advocacy, and I'm sure many of us around this room have done that a lot and it still is important, but it was direct contact. You tried to get a meeting with the decision maker. You know they've got a gazillion meetings. Margaret [McDiarmid] certainly knows that. You go to their staff and you try to get someone that you know that may know that person and could help you get the meeting. Then you finally get the meeting and you need – you've got 30 minutes to present your case – so you need to have a very solid case, a very solid message and make sure you maximize that opportunity. That's still an important part of influencing people, is that face to face opportunity.

Not only with the elected politicians but I always think it's so important to think about the staff who work with elected politicians. They are also very important. To make sure you develop the relationships and have good relationships with the political staff, and of course with the public service in whatever departments that you're dealing with, whether it's Health or Social Services. Because again, if you don't have their support, that can be a big barrier. Having their support can really help to facilitate the asks that you have. You need to think of all those different levels.

Then of course in your own communities across the province, the community leaders. Look at how you can as your local association if you're wanting to make an ask and working with the Province, have some influential community leaders who may not be working with you all the time but are sympathetic to your goals who could help you in your meetings, whether it's with your mayor or whether it's at your provincial MLA and can facilitate those as well.

Then of course many organizations, and I'm sure Lorraine was familiar with this in her previous roles as well, they do things like MLA breakfasts or events in Victoria where they try to bring as many of the MLAs together and put forward the case. I think the Association has done that. Those have to be very carefully done because you don't want to go to all that work and have nobody show up. Again you have to really work at getting people out to those events if you want to invest the time and money in doing it. Personally, I don't think it's the major part of the advocacy work but it can be very helpful and supportive if you have the time and resources for it.

You need to find your allies and your champions at all levels and not only in the public sector but increasingly I think at all levels, we're looking at improving our partnerships with the private sector as well. I know for some folks this is a bit of an anathema. But it's kind of the reality. Increasingly many private sector organizations are becoming much more involved, whether it's with NGOs or philanthropic organizations. Not only with just providing money but being more actively involved in supporting activities. I'm sure at the local level, you kind of know that. But that is opportunities, not only to help you with your fund-raising but also to help you with influencing the broader asks and that's really important.

As you start to work at looking at the decision makers you want to influence, you really need to have a background of who's onside and who's not. It's better, in my experience, to start with those who you think are onside or are sympathetic. In the

moment with our Chronic Disease Prevention Alliance of Canada, we're meeting with our federal MPs around some our issues. You find a vast array of differences in terms of their response. If you just go to the ones where quite honestly, you know they're not interested, you get discouraged and you start to think, "Oh I will never get anywhere with these issues."

I always think it's better to start with, start from strength, start with the folks you think have an interest in what you're doing. Obviously you've have, like Margaret MacDiarmid, you have George Abbott [former BC Ministers of Heath] in your camp, and also get their advice about who else you might be wanting to talk to at a provincial level and who could help you with your mission. Ask for their help. Not only ask for whatever the legislative change or the policy change or the fundraising project you have, but also their help in how to get your message across to their colleagues and get their sense of where the challenges will be as well. Of course you need to have those clear messages and evidence of what the impact will be of your ask.

What is sort of new, and I think you're going to be hearing more about this later today, is the whole use of social media and how that can be used to garner public support which then indirectly can influence decision makers as well. I'm not sure what the evidence is. It is still so new. But if you just look at the traffic, whether it's Twitter or some of the other social media, it is quite amazing.

I was looking at one yesterday my son sent me about Vancouver is naming "the bird". In addition to this being National Mental Health Week and National Hospice and Palliative Care Week, this was also National Bird Week. [laughter] Did you know that? Vancouver was having an online vote about the bird to be picked to represent Vancouver. I went online and voted. It was just amazing the number of people who have become engaged in this. There's been thousands. Who would have thought that birds were so interesting?

I was at an event last night with the mayor and, oh Trevor Linden last night too. That was impressive [laughter] and he's great. We're going to get those Canucks going. But as I was saying you may never know what may capture the public's imagination. Sometimes if you can come up with some idea that you can then utilize social media to provide that kind of support. Be creative and get some young people involved too. That's really important because they're the ones that know about all this. Those are some of the new ways that are important. Indeed attracting the younger demographic because for many of our organizations, we don't want them only to be populated by those of us of a more mature standing. [laughter]

I know again there's many challenges to that, when you think about the Camp Kerrys and the others, young people are concerned about the future of their families and their parents and their grandparents. Think of ways of trying to attract them and get them involved.

Then again with the traditional media, what they love – sometimes I find this really frustrating but it's the reality – is that they like stories that reek of unfairness. Some of them are unfair, the stories themselves are unfair, not only the situations they report on. Whether it's a husband and wife being separated and in long term care, that's always a big one that seems to get the attention. You have to be careful with that because that can be a two-edged sword. You may have a story about unfairness but you have to be careful that doesn't reverberate back and somehow misrepresent what it is that you really are doing and trying to do.

Those are both the new and the old priorities and approaches that you can be using as you influence people.

You have a great opportunity through your provincial association and the strength that it brings with the representatives of all your local organizations to put issues on the public agenda. The excellent reports that you – now the one today – are really going to help to document those stories.

I also think the whole issue around hospice and palliative care is really gaining momentum. I know when we're working in the trenches that sometimes may be hard to see. As I look back twenty years ago when I was involved politically, you hardly ever heard of the issue. If you document where the touch points were, the Senate report was probably an important one. But most of your organizations probably … how long has the longest one been around? Do you know? [Audience: Thirty years.] Thirty years? When you think about when you started it was probably well, probably tough going now but it was probably tougher going then for those who started it. Something very new and we didn't really think about it.

I think the issue around end of life care – you increasingly see it in op-eds, in newspapers, in people talking about it. I would say it's an issue that is still kind of on the cusp. It's not totally in the public face, in the public domain. But that you have a number of people, and people of influence, in the country who are concerned about it. I think this is an important time that you can build on that and take advantage of that to move it ahead.

Just talking about op eds, those of you who work throughout the province in your own local newspapers, that is also a really important way of getting messages out is to write op-eds and get something in your local newspapers on a regular basis about what you're doing. On your local media as well. It's hard to do it at a provincial and national level, but again, try to make sure you do get something in newspapers and on television on a regular basis.

I think while there is still some stigma from some groups who have difficulty dealing with end of life, that is changing. It's also one of the challenges probably that you have as organizations. Reaching out to broader ethnic groups who may not be part of the organizations now and help them talk about the end of life issues and help them prepare for the end of life issues.

Then finally around the advance care [planning] registry, I think that's … and I don't know how much work you've been doing on it to date and where you're at with it but … I would think that's something that you should be able to move ahead if you've got a case for it, you've got some idea of what the costs are. You already have looked at what some of the challenges may be around privacy issues which are really challenging, difficult ones these days. But I think that is one that is potentially really ripe and opportune to move ahead as well.

That's kind of where I want to start off and then turn it over to you to get your feedback and questions and start the conversation. Who's going to start?

COMMENTOR 1: This isn't a question but I do want to thank you for everything you've said this morning because it's very supportive of the people in this room. Sometimes when you're out there in the toolies, working alone and trying to get through the maze and trying to get people on side who aren't ready for that yet, it can be very discouraging and you can be just put it on hold. I have found what you have said today very helpful and very inspiring and I appreciate that. Thank you.

MARY COLLINS: You're all doing such good work and you need to feel good about it, what you're doing yourselves and in your communities.

Terri. Nice to see you.

COMMENTOR 2: Nice to see you too Mary. I'm thrilled you're here with us today. I guess on of the things when we all are out in smaller communities working and we're focused in our local communities, I'd like to hear your thoughts on – I'm trying to figure out how to frame this – but we have issues that are relevant at a local level then we have issues that are relevant potentially at a regional level with our individual health authorities. Then we have issues obviously that are relevant obviously provincially with provincial government and certainly with the federal government. I guess I'd like to hear your thoughts on addressing those different components because I have the sense that we're always stronger if we're all on the same page and moving in the same direction. If you might just comment on that a little.

MARY COLLINS: I know at an individual local level, I'm assuming that you work with your local councils and other folks in your communities. The health authority one is always challenging because it's, they're much bigger, and to find a champion within the health authority who can really support you is important. But also going to the boards of health authorities, I would certainly recommend that. Whether you get together with the other hospice associations within your local health authority area to ask for a joint meeting. You'd obviously have to agree on what it is you want to present to them. But I know, one of the other things is, I'm Vice-Chair of the Vancouver Police Board and we have started meetings with the Vancouver Coastal Health Board to focus on the mental health issue. Just because we brought our two boards together, it's had a huge impact and really moved the issue forward. I'm a great believer if you can do something like that.

The other thing you should be thinking about, and we've just in the BC Health Living Alliance [are] just finishing a report looking at the relationships of health NGOs and local governments. We've documented what's going on at the moment at the local level and what the opportunities are. I can see some particular alignment with what you folks are doing too.

Working with the BC union of Municipalities, not only working with your own local council but taking advantage of both the regional municipal associations and we've got a list of all their meetings, when they meet, but finding an opportunity to perhaps present to them. Also at UBCM at their provincial conferences that they have every year. We in fact have been talking about doing something like a health fair at one of their conferences trying to bring the health NGOs together to have some kind of a joint focus with the local politicians. That would be another opportunity because they certainly are very influential and another voice that can help you in the provincial government.

COMMENTOR 2: Thank you.

COMMENTOR 3: Good Morning. You'd mentioned just an increased focus on the private sector as well and corporate. What do you suggest as some of the advocacy efforts and the influencing change department that would be in our interest even at a local level to rally some of that private support and include that as we're approaching local and provincial government, and to have them onside prior to having those conversations? Are we more, does it increase our impact if we're a united voice from the start?

MARY COLLINS: I would. Ordinarily I imagine you look at private sector partners for fundraising. But why not also think of them as supporting you in your advocacy work and making it clear to them you're not expecting them to be a volunteer and all the time because they probably can't put the time in. But in some influential private sector person in your community that you may have some linkages with, and ask for ... make sure they're briefed obviously well ... but to go with you on some of the key meetings that you may have with government stakeholders or other folks as well. That can be very helpful. The same thing at the provincial level too.

I see that George [Abbott, former BC Minister of Health] has joined us too. Another great advocate and supporter of your goals. It's wonderful to have you here.

COMMENTOR 4: Thank you very much for all the information that you're giving to us. I am sure this is really going to help when we get back home. But I have this one question that, it's really getting to me. It's sort of a frustration level and I'm just wondering: is there any way that we can do away with the silos that we have at the provincial level, the local level because one shoe doesn't fit all. I was at an AGM the other day and I mentioned to Mr. Fassbender (current BC Minister of Education) that it doesn't work and he agreed with me and I thought, "Oh nice. That's a first step." But really, I live out in the boondocks and I find that it seems to me when I come here and I listen to all the wonderful things that people down here are doing and is there a way to help us along that line? The competition that seems to be happening. This money's fighting for this one and the other one is fighting. Where can we come together, in what way so that we could all work as a team and share the wealth.

MARY COLLINS: Are you thinking particularly within the hospice and palliative care movement?

COMMENTOR 4: Yes.

MARY COLLINS: Okay; alright. Not necessarily with the broader health community or .....?

COMMENTOR 4: That too.

MARY COLLINS: Because I think it's important.

COMMENTOR 4: The thing of it is, we seem … and I'm not sure if it's the numbers or something like that, but it's very difficult. And I'll give you an example of what I'm talking about. I found out about the "My Voice" booklet when I went to a specialist [physician] to find out. Now that information is there. That's the other thing. Why are we not getting that information? Why did I have to pick it up from there and ready for myself and distribute it and say, "Did you know about this?" I think those are some of the things that really concerns me and I'm sure it concerns the other people too. So help me. Is there a way that you could think to help us along this line?

MARY COLLINS: I would hope your provincial Association could help you with certainly some of that. That's the whole idea – to bring you together and to ensure that you are able to share resources and information and dealing with issues that are common issues across the province. I would think the Association is going to be the main mechanism probably to deal with that.

But you just raised a point that I also wanted to comment on, talking about silos. Another very important set of organizations that I think you should be continuing to work with would be Doctors of BC (formerly named BC Medical Association) and the nurses as well because they are very important partners. To bring them, making sure they're onside with the issues that you're dealing with and the advocacy that you're proposing. I know that increasingly primary care is being looked to as an area which can provide a broader range of information to folks both about health living and I would think also around end-of-life care and the advance planning. Opportunities to speak to and educate physicians are going to be very important and Ross [Sharpe, Sovereign Order of St. John's], you may have some views about that as well, I realize. And of course nurses. Next week is "Nurses Week" and I was at an event for nurses the other night. Every week is a week! They're such an important part of this whole process. If you have … something like the advance care planning … to bring those organizations on side with you

and have a joint voice going forward to whoever you think might be able to implement something like that, would be important.

COMMENTOR 5: Good morning. One of the frustrations that we have as a stand-alone hospice in Vernon is that we have our own individual contract with Interior Health [Authority]. Kamloops [Hospice Society] has their own individual contract with Interior Health and to a degree, we compete for funding. One of the issues that's brought forward by local politicians and provincial politicians is our organizations are all structured and funded very differently. One hospice in Vernon is going to be completely different from the hospice in Kelowna and different from the hospice in Kamloops. How do we go forward with a common voice when amongst ourselves we're not structured in the same way. It's very difficult.

MARY COLLINS: Do you get together with the other hospice organizations in your own health authority area?

COMMENTOR 5: We will be. Yes, so ...

MARY COLLINS: I would certainly recommend that.[laughter]

COMMENTOR 5: That is something that we're starting to go through the contracts line by line: "Why are you getting more funding for this when we're not?" We're now doing that cooperatively, however, getting that through to the Health Authority contract manager's attention is difficult for sure. We have had meetings with the Health Authority board members, we have had meetings with our local representatives [MLAs]. But as Donalda [Carson, BCHPCA President Elect] said a little bit earlier, it seems as though you're banging your head against the wall and we're not seeing much progress.

MARY COLLINS: I would certainly suggest to work together. I realize that if one of the hospices is getting a better deal than the others, that is very challenging. But certainly you're ... you need to think more broadly and think about how you're going to help each other in the broader movement across your region, across the province. So you try to lift all ships and put forward proposals that will enable that to happen. It takes time and if your health authority is not being receptive ... the other thing is through the Association just to find out in the other health authority regions, how are they are handling it and if it is as varied as you're indicating, then that would be a case for the provincial Association to be working with the Ministry of Health suggesting that there be some common approach. The problem is you don't want it to be levelling down; you want it to be levelling up.

COMMENTOR 5: Exactly. You have to be careful what you ask for.

MARY COLLINS: I know. You do have to be careful what you ask for. But you're not going to get, from my point of view, you're not going to get anywhere if you're all just competing with one another. I think it's really important that you find ways to come together and have that common voice, both at the local health authority, regional health authority level and at the provincial level.

COMMENTOR 5: Thank you.

COMMENTOR 6: Thank you. So I'm going to broaden that conversation with Interior Health, because Interior Health itself has a bigger problem. The three [communities] that were just spoken about are in the West Kootenays [Correction: Okanagan, west of the West Kootenays]. While I appreciate the concern of, are we all getting fair deals, there's the East Kootenays where Interior Health has said "We will not support hospice. Period. We will give you no monies." It's the same health authority.

[Exactly. That's kind of my face to it.] I'm a firm believer in when the tide raises, all ships raise. I'm a very firm believer in that. I don't want to take anything away from Kamloops, Vernon, Kelowna, however we have stats that say that whereas in BC, one in four people will be 65 [years of age] or over by 2034, in the East Kootenays and specifically Cranbrook to Kimberly, sorry Cranbrook to Golden, we have numbers that say that will be one in three in our region, and we get no funding.

MARY COLLINS: And you don't have any hospice?

COMMENTOR 6: We have three hospices: one in Golden, one in Invermere and one in Cranbook/Kimberely. And none of us get any funding. Castlegar has also been told that "You will not get funding." [Comment from audience] Oh I'm sorry. Then Castelgar does get it. But we don't. And Trail, sorry … and Trail and Creston.

MARY COLLINS: Have you ever been told why that is, what the rationale for that decision is by the Health Authority?

COMMENTOR 6: Personally, I have not. Don, have you been told? History.

MARY COLLINS: So you need to change history, moving ahead.

[Inaudible comment from audience]

COMMENTOR 6: Again, I think that's a place where yes, BCHPCA, there's a big role I think for BCHPCA in this very particular health authority. Because Interior [Health Authority] deals with it very differently from the other health authorities. I think that's an issue. But those of us in the East Kootenay, at least from myself, we don't know how to approach that because we're so small by comparison. Yet we have the numbers in a different calculation. Because we don't have the population of Coastal or North or Fraser [Health Regions].

MARY COLLINS: I realize that. But again, that, I think, would be a great issue for the provincial Association to take up with the Ministry of Health which might be at the bureaucratic level, certainly to begin with to find out what is the rationale. Shouldn't there be a provincial plan? Maybe Margaret or George can speak to this more effectively but that there's some equity across the province in terms of providing hospice and palliative care and the funding of it. If there isn't, then that becomes an issue whether you want to take it, and I wouldn't suggest you take it public at this point, but at some point, if you never do get any satisfaction, it is something that you can go public with.

COMMENTOR 6: Thank you, because I think that is a concern.

COMMENTOR 7: Hi. My name is Joelle Bradley and I'm a hospital physician and work in our Advance Care Planning Group in New Westminster with Leslie Rodgers. Just recently – maybe a month ago – the Canadian Diabetes Association came out with this really innovative thing, this declaration and constitution of patient and health care providers rights and responsibilities for diabetes. There were eighty points in there. I was so disappointed that it was nobody's right or responsibility to talk about advance care planning and planning for your last chapter. So I'm thinking I need to write them a letter. I don't know how to, because they're probably influential people, how to influence them. Because sometimes it seems with chronic disease, you always talk about healthy living and how you'll beat this thing. But none of us will beat our final chapter. Any tips for influencing the Canadian Diabetes Association, because wouldn't it be great if they were to embrace advance care planning.

MARY COLLINS: That's a really good point because again from my own work, our alliance [BC Healthy Living Alliance] represents the chronic disease: cancer, heart and stroke, diabetes, lung [disease]. Our emphasis is on keeping people healthy obviously. But all of those organizations are in fact dealing with people suffering from those diseases and with end of life. I know they have an interest in end of life issues. So let me think about that. It might be something that I can raise with our members, whether there would be an opportunity for a briefing, or for your Association to come and meet with our group at some point to talk about some common interests as well.

I'm a great believer in – someone mentioned about silos – breaking down silos and getting people to work together collaboratively on these kinds of issues. And obviously there are some mutual interests. There may be some competition too, but let's at least talk about how we can potentially work together. I am familiar with the diabetes one because I was at the launch of it in Ottawa and that's an interesting point, that it didn't really include end of life issues.

COMMENTOR 2: I just wanted to respond Mary if you would let me real quickly to the issue that was raised around Interior Health. Terri Odeneal, I'm with Vancouver Island [Federation of Hospices]. One of the things that we've done on Vancouver Island, and there are a lot of people here and someone from our health authority also, is all the hospices have come together to work with the Health Authority and really try to find the common threads that we can do that. It's been extremely helpful and beneficial, I think, to do that. It's not that we don't have differences sometimes. We have local issues that we need to work on but then we also have regional issues and we've been able to do a lot around advance care planning on a regional basis. It is possible within your local area. When you start getting from Vancouver Island to all over the province, a lot of the times, just geographic size is different, access issues are different so I don't know that everybody can do it all the same. The local area stuff does work. Maybe in Interior it doesn't work because you have more boundaries and it's bigger so there are more areas, but it does work.

MARY COLLINS: That's good to hear that you've done that. Were there, or are there now still inequities in funding?

COMMENTOR 2: There are inequities in funding but for the first time, we were actually able to negotiate ... we've been getting, we came together and said, "We want all hospices, regardless of size, regardless of how many people they serve, to get the same amount of money" and for several years now we've gotten money based on year-end slippage. The first time, what happened this year for the first time, was that we're actually part of a core funding agreement where each hospice gets the same amount, again regardless of size. We see that is basically, "keep the door open" kind of money. It's not a lot of money but for the first time, it's coming from our health authority and it is equitable amongst all the hospices, so ...

MARY COLLINS: I think that would be a great example to share with the other, with folks from other regions around the province, of how you've done that.

COMMENTOR 6: What I was going to say is, I think your point is really well made about unifying and your point is really well made about the size of the region. As Don likes to say, we're talking about a region the size of France, for Interior [Health Region]. We do have three distinct [sub-regions:] East Kootenay, West Kootenay and what's the third? I'm blanking out ... Okanagan, thank you, for the Interior. And there are lots of hospices. One of our big problems I think is that Interior Health doesn't speak to Coastal Health, doesn't speak to ... They don't share the documents that would be so valuable that we've just discovered. Is there a way for us to actually speak to the health authorities about sharing their information with each other, finding out what each other does? I don't know if there's a way that we can influence that. [laughter]

MARY COLLINS: Have we got an answer here? Good! We're getting the conversation going. I've got some thoughts but would you like to respond?

COMMENTOR 8: I'm hoping my hospice friends will back me up here. I'm from Island Health Authority. [laughter]

MARY COLLINS: Oh good.

COMMENTOR 8: I'm speaking over here to Interior Health. I think there are opportunities, absolutely, for the health authorities to come together. Champions as you speak of. We currently have an End of Life Working Group where there are key members from the health authority that come together to discuss issues around end-of-life care and a key contact in Interior Health has been connecting with us to find out how are we communicating with hospices, what are we doing. I think there is an opportunity. I am happy to take that back to the larger table and see if we can create some more linkages. There you go.

MARY COLLINS: I would just add to that. I know that there are other tables because we're [BC Healthy Living Alliance] involved with several where representatives from the health authorities are coming together around issues and my understanding is that the Ministry of Health is really encouraging this. I think this, and I don't know that you, there must be a contact at the Ministry of Health that you deal with. Whomever that is would be someone that you also should be talking to just to say, "Okay, can you organize an opportunity for the Association to speak to a meeting of the health authority reps too."

COMMENTOR 9: Thank you very much for joining us and for all the information you're sharing with us Mary. I just really want to take the conversation to perhaps a national level rather than other than just the provincial or regional levels. I have had the opportunity to work on a couple of national committees around end of life and primary care and the integration of the two. What I discovered is that there is a tremendous amount of activity and initiative and innovation in some other provinces around end of life, hospice, palliative care, bereavement etc. I was wondering if you have any salient points to make in that regard and also perhaps you could point us in the best direction so that we in British Columbia and BCHPCA in particular can benefit from all the work that is being done elsewhere in Canada so that we can come together perhaps more as a country rather than just a region or as a local municipality. Thanks.

MARY COLLINS: You do have your Canadian Association still don't you? I don't know how active it is. It's very active? Okay. So that would be the first line I would think both in terms of sharing information and advocacy at the national level. I think we have to be realistic in recognizing that at the federal level, there isn't a lot of funding for health. They basically say the provinces are responsible.

But there is the FP, the Federal Provincial/Territorial Minister's Table where they deal with issues of common concern. I don't know if end of life or palliative care issues have been on that table or not but that would be another way to try to get both the bureaucratic and the political level some, looking at what are some of the common needs across the country, common issues, if it is a fact of trying to get a national advanced registry. Would that be something that would be feasible or would be better than each jurisdiction doing it on their own? Or what are the other common issues that should be addressed at a national level.

COMMENTOR 9: Yes. I'm quite interested in the issues as well. I'm familiar with the Canadian Hospice Palliative Care Association and I think that they do very good work. But what I found to date is that it is quite focused on Central Canada, Ontario in particular, so it's very difficult for us to translate that information into our own local environments. What I'm really

thinking is that there should be or could be or hopefully will be a way that we can understand specifically what they're doing from the perspective of fund-raising, from the perspective of initiatives on the ground assistance and translate that into our environments. I don't see that coming out of the Canadian Association as yet because it is still so focused on what accomplishments they have undertaken or been successful in their own province, so ...

MARY COLLINS: I will really suggest it's kind of up to you folks to try to change that. Get your people onto the board or the executive as active participants in your national Association to make sure that it does in fact take into consideration issues from the West and the Maritime provinces as well as central Canada. It is supposed to be your Association and nobody else is going to mandate it I'm sure to do that; you have to do it yourselves.

COMMENTOR 10: Thank you. Actually most of what I was going to say has been said. I would want to go back to the question of silos, particularly silos between elements of the health care system. It's a big honking system. It's worse than herding cats. I worked in it for enough years to know. But one of the real advantages that we have as hospice societies in individual communities is that when we assign a volunteer to somebody at the end of life, they stay with that person through whatever happens to them, through wherever they go.

If there is one group that can work through this morass and give advice and give direction to people who are under a lot of stress, it is us. I think that it behooves us to turn that into an advantage when we're talking to people like health authorities. That is a service that we can give and it's a value added that is really tremendous not only to the individual that we're serving but to the organization that's trying to serve them. Because the health authorities are actually trying to do the best they can to make that person's end of life as good as possible. I think we should look on that as a positive thing and not necessarily a negative thing.

With respect to the question of the equity, there's a lot of inequity in the world and the simple rule is that the further away you get from Victoria, the more money falls off the train. [laughter] By the time you get to the east, the very east, and we're so far east that we're in a different time zone, there's not that much money left. That's why there are inequities. They're historical and it's not just us. If you go up to the northeast, you'll find pretty much the same thing. That's why every once in a while, the peasants get restless and say "Well the hell with it. We're going to join Alberta." They've got the oil too, so maybe we should. [laughter] Anyway, that is a problem.

But the other, one of the advantages we now have is that there's new technology so that distance isn't what it used to be. We have video conferencing, we can get together electronically. We can get our own act together and I think it behooves us to do that. It's one thing to complain and say, "Geez Lorraine. Go and get this for us, got and get that for us." But the first thing we have to do is get ourselves together and figure out what do we really need and what do we really want. Because frankly, what works in Kelowna, might not work that well in Cranbrook or ... So I don't think we want the result of this to be a cookie cutter that we all have to be stuck into. We want to have some flexibility but we want to have some equity as well.

MARY COLLINS: I think those are really good points Donald. Yes, it is a lot easier to talk to each other now. You can use, well Skype even came out last week with some way that you can put ten people together on a free Skype call and use those technologies to keep your conversations going . You'd think with that then the money shouldn't fall off the train as it goes east.

COMMENTOR 11: I just had a real quick comment as somebody in Kelowna. Often you hear a lot of this and I think that one of the first things they said today is really something we all need to remember is aligning the asks to the priorities of who you are

asking. If you go to a person who is in a health authority where money is something we obviously all care a lot about and you go and say “I need more”, they’re going to protect what they have. But if you go saying “I would like this in order to provide care and here’s what I’m already doing and imagine what I can do with more resources”. I think it’s really important to focus on what we do well and align our asks appropriately. I really appreciate that was one of the first things you said today. I just wanted to make that comment.

MARY COLLINS: I would think and I haven’t read that study [BCHPCA Hospice Palliative Care Services Study] in detail yet or some of the other work you have. But my sense is that the care you provide in the hospice movement is much less costly than keeping people in acute care. You’ve got a great argument. There obviously are start-up costs and things that you people have to address, but I think you’ve got a great case and again coming back to Donald’s point, your involvement of volunteers is just amazing. Again something that people of influence like to see because they represent real people on the ground. Real voters on the ground.

LORRAINE GERARD: I think this has been an amazing presentation and before I formally say thank you, I’ll do an electronic introduction between you and Joelle so that you can follow up on that diabetes initiative. Just as an, so that my Board doesn’t think they have to rewrite my job description after this [laughter], BCHPCA has actually been invited to participate in the steering committee to implement the End of Life Action Plan [Provincial End-of-Life Care Action Plan for British Columbia] and so that’s in the works and so we will be able to bring the membership’s concerns to the table. I think that is the route to go and I think we’re all on the same page. We all want services to be available when we’re going to need them. And we’re all going to need them.

On that note, I’d like to thank Mary for coming and continuing our conversation and responding so well to all of our questions and giving us good practical information and also information from the heart. As a token of our thanks … [gift presented]. Thank you very much. [applause]

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