Transcript: Meeting with Novo Nordisk CEO Lars Jorgensen

Lars Jorgensen (Novo Nordisk CEO): My identity has been helping people with diabetes, for the next 90 years that ought to be the case because that's who we are and what we do. Per manual we are a foundation that was established by the founder, and the sole purpose of that foundation is to run the company and support diabetes care activities. So that's who we are. And then we have this situation where, you know, maybe not the majority but for many patients in the U.S. there is a significant issue in terms of affording insulin, which is a bit of hitting my identity as now heading up the company because that's just what we've been securing for many years. And then, you know, we've had many questions about and what to do, what can you do? So we decided to take a couple of days just listening to what are the pain points and then having this ambition to try to figure out what can we do. It's a complex healthcare system which is a part of the challenge but our drive to do something obviously also comes from understanding what are the pain points of the system. And I don't expect that you have the magic bullet that will solve it but any perspectives on what would make a difference for the patients in the U.S. Healthcare system what would be relevant to consider, I would highly appreciate that.

Kasia Lipska MD (Endocrinologist, Yale University): I'm happy to start and then we can trade off. So Lars, I'm an endocrinologist, both a clinician and a researcher and I see patients with Type 1 and Type 2 diabetes. My career plan was not to talk about insulin cost. Ever. But it really, it was starting to come up in my conversations with patients over and over again in my clinic. People telling me that they couldn't afford insulin, bringing me their bills to show me how much they were paying for insulin, telling me that they don't want to increase the dose, you know, all sorts of different stories about how much it was a struggle for them to pay for insulin. So that really started my interest because I thought, my job is to help patients, I care for them and if they can't afford what I'm prescribing that's not good for anybody.

Jorgensen: The patients you see are, from a societal aspect, broad? Across...

Lipska: It's a mix of patients. So our Yale Diabetes Center sees about 3000 patients a year or so. Just like most diabetes centers it has people with Type 1, about 40, 45% of people with Type 1, and the rest of people have Type 2 diabetes. It's a mix of people who are covered by Medicaid and the state insurance, Medicare. A lot of my patients are older because my research interest in diabetes are on how to treat older people with diabetes. And then private insurance, I very rarely see people who don't have insurance because they probably don't come to see me. So it's a mix of different plans. I tried to compare, because these stories made me want to really document how often people were having trouble with diabetes, which led to the survey we conducted in our clinic.
And when we conducted that survey we really looked more closely at our clinic, does it look different from other places in the states? Is it representative of patients in general? And we compared that to these nationally representative cohorts of people and the difference was that we had more people with Type 1 compared with the general population. But otherwise it was a mix. A similar mix to what's represented in the United States. In that survey we asked people over the last year, did you use less insulin than prescribed specifically because of costs? Not for other reasons but because of cost and one in four of the patients said that they did.

So we were talking, well maybe this rationing issue is more about people who are not able to access healthcare in general. But the survey suggested no, I mean it is an issue for people who can't access healthcare, but it is a problem even among people who are seeing healthcare professionals like myself who have insurance. Almost entirely the people I was seeing actually had insurance and even among these patients one in four were rationing. So that's it.

We tried to also ask how much they were paying for insulin. It's very hard for people to estimate how much they're spending so that data is not very useful. But yes, the issue is co-insurance copays, high deductible plans. It’s not only an issue for people who I wasn't seeing, people who are uninsured and go to the pharmacy to buy their insulin but even among people who are insured, people who are on high deductible plans, people who have relatively high co-insurance, it's a hit for them.

Again I see a mix of people and the people with type two diabetes typically need much higher doses of insulin because they're more insulin resistant. So just the sheer volume of insulin that they use, even when it's not, may not seem expensive it adds up. It's a lot of money when you need to use multiple vials, some people use a hundred units a day, 200 units a day. It's not unusual, so it adds up in terms of costs. People are really struggling with this. I think that the survey really got a lot of media attention because before we hear stories from people about how much they struggle but I think to have the evidence that it's not just these stories, it is really more widespread was really important.

Jorgensen: So do you feel this has changed over the past few years? And go you see why it has changed?

Lipska: On why it is coming out now? I don't have the data from before to say, but I think it is increasingly an issue. But, again, I don't have the data to back this up, I don't know if you do. So, we also see patients who come into the hospital with complications, come in with DKA. The story often is, “Oh, I was taking this, it was working, but now I haven't been able to afford it. And so now I'm off of insulin.” This is what happens. So it's terrible. It's a terrible, terrible situation. [To Karlynn Holland] I'll let you maybe speak to that some more.

Karlynn Holland (T1International and New York #insulin4all patient advocate): We feel it's directly tied to the list price and we feel that for a lot of reasons. The US Healthcare system exposes patients here to the list price and that is an unhealthy financial burden that translates into unhealthy physical outcomes for people. As the list price continues to go up we're seeing increased rates of amputations and blindness and things are just kind of deteriorating for a lot of people. I'm one of the few who is in a fortunate position, I have very comprehensive health care and I think my health shows that I've never been exposed to paying full price or paying these high prices. If I had to tomorrow pay $250 a vial for insulin, I would quickly be priced out of life. I would have to move home with my parents. I would have to take out loans. I would be desperate to find a job to get me back to having comprehensive health care.

And the other thing we see is the most vulnerable populations are people in transition. So that's young people age 24 to 26. They get priced out because they lose health insurance through their parents but they're also early in their career where they may not be at a place yet with a job that has the kind of health insurance I qualify for through Columbia University, an Ivy League institution or that Dr. Lipska has through Yale University, another Ivy League institution. We're exceptions to the system here.

Just this week a young woman named Jada Louis lost her life to DKA. She couldn't afford insulin, she went without it for several days, went to the hospital in DKA, was released, could not afford to refill her prescriptions, and she died. And it just is becoming more common and we want this to end. I am applying to medical school next year and I think everybody deserves that opportunity to not just survive and live but to thrive, to be a full active member of society.

And I don't think anybody in this room disputes that. Obviously you're here listening. You invited us and thank you for that. I want all of my peers, I want every person in my patient community, to have that. I want them to have that opportunity. And when we are burdened with these financial costs it is not possible. We never have the ability for savings, retirement, to buy a home. Those are things that the Type 1 diabetes patient community in America is losing. And those are the things that make your life your life, you know? If we have to pay $1,200 every month that's money that is not going into my retirement plan, I can't travel, I can't help my parents if they become ill because everything I make goes into caring for this condition.

Jorgensen: Thanks for sharing.

Lipska: And again, it's not just an issue, it is absolutely huge issue for people who are uninsured, but the list price also affects how much people pay for co-insurance and those are high deductible plans. So among my patients who, some of them are younger, but a lot of them are old, you know, middle aged or older, the typical age of Type 2 diabetes. And many of them work, work very hard. They don't qualify for Medicaid, the state assistance, but they don't make enough to really be able to afford insulin.

And you look at your patient assistance programs, they are, we're glad they're there, but it's often very difficult for us to find a patient who qualifies for that aid. I think the income level is about $50,000 for a single person who was covered. But when you think about the price of insulin that person needs to buy, who can afford that?

Jorgensen: You know, if you make less than 50,000 as an individual, -

Lipska: You're covered.

Jorgensen: You're covered. Get it for free.

Lipska: Yes. But I'm saying what if you make 55, how can you afford it? Right? So again, the people who are, who make the least, they're actually often covered by the state and in my state they have access to insulin. It's really the people who make some money but not enough to pay for an expensive product like insulin. So they really struggle and they are appropriately frustrated with the fact that ‘I am working, I am working so hard, I have these two jobs and I still can't make it. I still can't make it ends meet.’

Holland: Or, to add on to that, they're forced into a position of limiting their income. Their economic growth is stunted because they must continue to qualify for your program or for the low income insurance available through the States. And we see that a lot among not just Type 1 diabetics but others, but specifically for us. People who turn down opportunity because it would disqualify them for the programs that allow them to afford to stay alive because the additional income isn't enough to cover the high list price or the insurance premiums.

Jorgensen: So it's blocking their development and growth.

So what, what'd you do? Like what would you like to see from us? What would you think would solve it?

Holland: My wildest dream, if I'm dreaming my biggest dream, is that all insulins including the rapid insulins are available over the counter without a prescription at an actually affordable price. I know there's a lot of components to that, not all of them are under your control, but that would allow patients to decide which formulary works best for their body to meet their needs. I know people who are allergic to Humalog, they much prefer Novolog and I know vice versa. It takes it away from the insurance companies and it makes it so that patients are now actually making a market choice.

It also is a patient safety issue. It takes time to qualify for your assistance programs and in that time you still have to stay alive. I go on vacation to another state and something happens, I drop a bottle of insulin. I would have to go to a doctor to get a new prescription and then go to a pharmacy and hope that it's open to get that new emergency refill. I'd likely have to pay 100% of whatever the list price is if it's before my refill time. We're doing a lot of work, my organization [T1International], to fill those gaps and loopholes. But if it were just available over the counter at an actually affordable price then that worry is alleviated.

Jorgensen: So, I guess in most countries, including the US, at least the modern insulin NPH and R prescription, funny enough you mentioned, you can get over the counter. I'm not quite sure I understand why...

Todd Hobbs MD (Novo Nordisk Chief Mission Officer): It was around before the FDA. Basically it's the grandfathered in.

Lipska: It was grandfathered in. So it's, it's a funny, it slid under sort of a different regulation that was there at the time

Holland: For people with Type 1, NPH and R is an emergency only, temporary solution.

Jorgensen: So you can say, and the limit in shows is linked to insurance, formularies are linked to the whole. This is the model of rebates, et cetera, so if there is to be free choice, the business model would have to change.

There's no secret that we are supporting the potential rule of making rebates illegal. So all business would be done under net price and if you do that then the insurance plans would not have an incentive for favoring one product over the other without having thought it perfectly through. I would guess that that means all products, or main products, would be available and it would be our job to make sure that we bring innovative interest to the market that's differentiated and does a better job. And then there's competition on both price and clinical differentiation. And it's a choice between the physician and the patient.

Lipska: I think choice is really important, but I think that, you know, again, you're right that in our healthcare system we've created a system that limits costs by narrowing the choices, somewhat doing generic substitution over the counter and so on. So I would like to see everybody who needs a specific insulin get that but for many patients it may not be that different, right? There are those where it is not different. I think that getting the least expensive product is important to contain overall costs. But I think what we're both saying [Lipska and Holland], which I am not sure you heard from others you've met with, is that it is really the list price. I know net price and all of that and we've read your position statement and understand the complexity, but it is really the list price that is the issue. And if that came down it would solve a lot of the downstream problems for patients who are both insured and uninsured.

We understand if you bring your list price down, you may be in a worse position in terms of competing for your formulary placement. But we also talked about the fact that at some point somebody in the system has to make less money in order for patients to stay healthy and survive. And so this is an opportunity for your company to sort of lead the way. One of your tenants is social responsibility, I think it's really important that you are able to commit to both financial responsibility to your stockholders, but also social responsibility for the stakeholders.

Jorgensen: I agree. And that's why I'm here. So you are right if tomorrow we lowered our list price, and it has to be significantly or else it doesn't really matter, right? We would be a less attractive supplier because we would give less rebates and the insurance companies would favor a product that kept giving more rebates. So it would most likely mean that we would not be on formulary. So our product would not be available for the many patients who get it today in the established supply chain. We have to find a way where we make sure that still the majority of patients who have coverage can actually get our insulin and then find a way to make sure that those who have, say, a very high charging insurance scheme design, meaning they pay list price, that we have a way to make that list price lower.

Because we have to solve for both. So if we only solve for those we talk about now and we did that by lowering the list price and we could, if we stopped giving rebates, we could lower our list price significantly but if we did that all the billions of dollars we pay in rebate is missing to fund other types of medicines. So we have a situation where last year we paid $17 to $18 billion in rebates, a mind-boggling amount, so $17 to $18 billion we paid in rebate. Those rebates go into insurance companies and help pay for medicines not for insulins but for other kinds of medicines. So there's tough competition, contrary to what many believe, it's actually tough competition among the insulin manufacturers that drives the rebates up and that amount of money is being used to fund healthcare systems outside of insulin. And then, unfortunately, increasing amount of diabetics are asked to pay the list price or part of the list price. So when they do that they pay, say rough numbers, three times more than we got for the product. So we have a situation where those that we serve, people with diabetes, are struggling but I'm also frustrated because the business model is not sustainable for us either. So we have to find a way to change it.

Lipska: So how can you lower the price at the pharmacy counter for those people who are stuck? But it's not just people, again, it's not just people who are uninsured.

Jorgensen: No, that's tricky because, you know, if it was just uninsured you could say we had the patient assistant program or we could have a kind of impact in a cash offering, a relative cheap product or low price for those who pay out of pocket. But that would not help those who are in high deductible plans because you have to do something that's inside insurance. And so it has to be something that gets on formulary with a PBM for some insurance companies for that to count against the deductible. Because if you just find the insulin outside of insurance, it's just strips and everything else and has to fill up the deductible. So it has to be some solution where we somehow get insurance companies to collaborate with us in getting lifesaving medicines like insulin into a better position than insurance plans.

Because if we have tactics to make sure that all products are on formularies and...First of all by patients or sometimes insurance plans they want to exclude certain products and there are proven tactics to do that. So if we all kind of fight each other to do that the patient is paying and paying the price of not getting access or having too expensive insulin. So my ambition is to do something together with the supply chain so our direct customers, so it becomes a collaboration. And some logistic in the effects that it brings to patients.

Lipska: I would imagine that an insurance company would be very interested in a product that has a lower list price and thus exposes public patients to a lower out of pocket costs because in the end patients would be able to adhere to the therapy much better in that situation. Again, we know that patients are not well adherent to the therapy because it exposes them to the costs.

Jorgensen: What insurance companies could today say for a product like an insulin is accepted for the deductible so if we say that staying in compliance with your treatment, you mentioned your glucose later will reduce the risk of ketoacidosis, would reduce the risk of amputation et cetera once again would save costs for insurance plans over time. One would think they would have a big incentive to do that already just because they could. They could say when you get a high deductible plan if you have a chronic disease like diabetes insulin is life-saving for you so it's actually exempt from your deductible.

Holland: Wouldn't it be easier for them to sign up for if the list price was cheaper? Because right now I feel like the insurance companies don't want to do that because it's expensive.

It's money out of their pockets. And if the product were priced much, much cheaper, wouldn't they have more of an incentive to say, okay, we cover this?

Jorgensen: If, if we tomorrow sold our product, we've moved on list price to net price we would become much cheaper for the insurance company.

Holland: How much would that be about?

Jorgensen: I'd say a third.

Holland: Ok. Still quite...like about a hundred dollars US dollars?

Jorgensen: Yes. So they would then, you could say the, the amount of rebate we pay them today, that would from that period of time be linked to the insulin. Today they use the money for something else. So the rebates we pay are being used to pay for other diseases. So when they pass on, say the list price to the patient, that means they are actually getting three times what they paid for it from us. So the diabetic is actually paying for other types of treatments.

So, it's a situation where we have to do something together with them because they could today actually say that the rebate we already pay them actually follows the product all the way to the patient without that costing them they would just charge the same amount as we charged when we sold the product but today, it's being, the plan designs are such that, when you're under deductible for instance or if you have a copay that's linked to the list price. And that's not something we have designed that's an insurance plan design. So, if we sold it at say a third, then the insurance plans would lack the $17 to $18 billion dollars that we paid them in rebates that is used for something else. So the short term risk for the central companies that lowers the price is that we would actually be kicked off formulary because if you used, say, a Sanofi product or the Lily product, you would still get the rebates that's funding something else.

So you can follow me. That's why one thing to consider is an authorized generic where you introduce your own biosimilar products and you could do that at a lower list price where you gradually move patients to that. So it doesn't become a hole in the budget of the insurance company overnight, right? But gradually there would be a transition to that. And if we do that in a way where they actually have time to adjust to it they would be most likely to actually put that part on formulary. So Lily lowered their price on this authorized generic but my knowledge is its not getting on formulary. So you can't really to get access to it if you're under high deductible plan

Holland: It's even a little worse than that. Our organization [T1International] called around to pharmacies in Arizona and not a single one is stocking it. So it's not even, no, it's almost like they did it for PR and it seems very bad faith. From where I'm sitting as a patient, it does not seem like it was an honest good faith effort they put forward. But we are very interested to hear about anything you're considering that will improve things right now for patients like me because we don't have a lot of time to wait. I live everyday afraid that I'm going to get priced out of life and a big part of my decision to go back to school was to go into a profession where I felt I could always afford and have access to the care I'm going to need. Not everybody can do what I did

Jorgensen: Not everybody can go to med school.

Holland: Yeah. Not a lot of people go from being a sculptor and in one day say, "okay, I'm going to go to Columbia University and finish premed." I know that that's exceptional.

My family is always worried, you know? My parents especially. They are fortunate to be able to retire, right, but as a family we have discussions about can they work a little longer to save up more money in case I'm ever going to need that kind of help. And I just find that absolutely heartbreaking. That shouldn't be the way.

So, is there anything coming up like a generic or discussions? I mean if you stood up and said you were going to be a leader and lower the list price knowing full well that it was going to cost the company money, I as a patient would publicly stand up and say they're doing the right thing. Listen to them, please pay attention to this and work this out.

Jorgensen: So, I'm not shying away from doing anything that costs money. I'm really trying to figure out what is the solution that we're working in the system so it actually gets to the patient and today, the last five years, the price we get for the insulin we produce is going down by double digit percentage points every year. So, the price we get for it, there's no other place in the world where's going faster down than it is in the US.

Holland: So the list price is going up?

Lipska: You mean the net price?

Jorgensen: Yes, which is the price we get. Yeah. So, if I have... fast forward say 10 years, if the current structure continues, insulin will be so low priced in the US for the manufacturers that some would probably start considering whether they want to be part of the market or not. And such is the market where nobody will invest in the next generation of insulin. And that's, I know you have the challenge as a patient now here, but when I look at the...we've been spending 19 years and doing what we do now that the structure has to change because there's not waiting for the patients today. We still have a good business but if I think 10 years out the interim pricing would be at a level where nobody can justify doing innovation. So it's an absurd situation where patients are struggling and the complexity of the system means that we are not solving the challenge.

So, on a yearly basis we are already getting less for our products. So it's not about, you know, getting more or anything. It's just finding a way to those competitive dynamics, which is tough and right on price. Which is okay, because Lantus is off patent. A biosimilar comes in and that means in the basal category there is tough competition. It's also in the fast acting category, Humalog or Novolog are fighting on price. And we want to see the pricing going down so we get less and less for our products, so we're comfortable with that. We just have to make sure that when we get less, the patients should also pay less, not more. So there's a perverse market structure that means that the drug categories in the U.S. has the toughest competition. That's where you have the highest rebates and those rebates are then used to fund health care in other disease areas.

Lipska: But Lars it's hard for me... I appreciate that argument. I've heard this argument before, but when one looks at where the money goes in the system and the prescription drug business, I suppose there are different ways to estimate it, but from what I've read, the amount of money that flows to PBMs and insurance companies is relatively small compared to the amount of money that actually flows into pharmaceutical companies. So it's a little bit hard for me to get to get behind this. I understand the complexity and understand the, the issue at hand, but your company's still incredibly profitable.

The PBMs are profitable to some extent as well. They do make money, but I think that there's been greater scrutiny in making sure that the money that PBMs make goes back at least to the insurer and it's not passed on completely to patients but in some ways it is through potentially lower premiums. So I just, I mean, I, I feel like we often hear this argument like nobody's gonna make medicines anymore. The innovation is going to stop. But the truth is that the profits of the company are still tremendous. And I think it depends a little bit how you get to this estimate of who's paying for what and what the net price is and how much things really cost. And it's very hard to get accurate estimates because nobody has any transparency in this.

So I appreciate that argument, but I still feel like we're looking to you because you hold the key to this because you are the person who actually controls that and you have great influence and can be a leader in exerting pressure in order for that system to work for you. But I think somebody's got to step up and do this. Otherwise we're not going to go anywhere with this.

Jorgensen: Okay. I hear you. And that's why I'm here, to listen to the pain points. And, of course I'm trying to figure out what is the best solution. And I know that nobody wants to listen to a profitable corporations whine about it.

Holland: It's hard. I have to say...

Jorgensen: I fully buy that. I'm just trying to get you a few perspectives and we paid in the US last year, on average, 68% of rebates. And on insulins its much higher. So, I can tell you a lot of money is moving to supply chain and that's fine and that’s the market structure. And we'll figure out what we can do within that. And we'll be looking at different options. And then we will be making decisions to change it. But I hope you also accept and, maybe, believe me when I say that if we just tomorrow lowered our price to what we actually get and say that we'll pay no rebates most likely the majority of your patients will no longer be able to get a product from us.

Holland: I don't know that I totally believe that. Okay. Because there's part of me that feels that if you made it cheap enough, who cares if the insurance company covers it? It might be cheaper than what my insurance company covers now. You could easily set a price that undercuts what the insurance, copays, and prices passed onto the patients are.

Jorgensen: So, what is your copay?

Holland: It depends on the plan I have. My current plan, which is some of the best insurance coverage I've ever had, I paid $25 for a three months’ supply. So $5 a vial. We don't know what cost is here and I don't know if you're willing to share with us what it costs to make and distribute a single vial of insulin but by estimates from what we've read in reports it's $7 maximum. I believe Novolog was first released at $40 a vial. If I had the plan I had last year where I had to pay about 10% until I reached a deductible, $40 a vial would save me money. Actually, I would be paying $200 instead of $250 or so. And so my insurance doesn't want to cover it, but it's cheaper and it saves me money. You have my business and uninsured people now have affordable access to your product.

Jorgensen: Yup. Yeah. The copay you have you could not produce insulin for that price, that's for sure. But of course, probably I'm not going to talk about innovation or that because that's what you heard from many already. But it's, you know, I believe there is a need to be a market for, well, maybe another question to you, do you feel the insulins that are available today are good enough? Are you looking for more innovation or are the insulins available today, are they what they should be?

Holland: So I'm very excited by the frontier of smart insulins, that change confirmation and hypoglycemia and are no longer active. That is a huge quality of life improvement. Having the rapid insulins that mimic the phase two insulin response is a huge improvement over NPH and R, no question about it, but still leaves people with a lot of technical issues. I pre-bolus every meal so that I can line up my carb load with that phase two response because my body doesn't have the phase one rapid response and the very rapid insulins that could be innovated? Yes, we want that. We do. But we want it for everyone.

I'm not willing to let my peers die so I can have a cure. I'm not willing to watch low income people suffer and have short life expectancies with painful outcomes so that I can have a better insulin. That seems very unethical to me personally and to many people in my organization as well.

Lipska: I think that's a great answer. And what I was going to say, is it is dependent at what price? I think that what's happened is yes, insulins have gotten better over time, but the question is, has that increase in price been justifiable for the improvement that's been produced? I think oftentimes, we question, given what we're struggling with, what we're talking about today. So, if innovation was bringing well-priced drugs to the market, great. But if it causes a crisis where, again, people are having problems with access. No.

And I think we've seen the human insulin versus the analogs. And as you know, I've published on this and I'm interested in comparing and really understanding the differences. And I think it's very different for people who lack any insulin production, people with Type 1 diabetes. And it is different for people who have Type 2 diabetes who often don't need very sophisticated insulin.

That the peak lesson is often diabetes can be well-managed with these cheaper insulin products. But I think, what I see is that you all have convinced us that these newer insulins are so much better that we hardly ever use human insulin. Don't even know how to. We also don't have pen devices for when you go to get your ReliOn, that's the cheap NPH and Regular, you can’t get that in a pen form, because it's going to be much more expensive

Jorgensen: There is a pen we have launched this year -

Camilla Sylvest, (Executive Vice President, Commercial Strategy & Corporate Affairs):
- That's at $25.

Jorgensen: Well it’s a bit more expensive in a pen because there's some cost to that, but it's still affordable.

Holland: Is it the 70/30 mix?

Jorgensen: Yes

Lipska: So I think having these products is important because they can be used and can be cost effective enough in a portion of the population, but they don't solve the issue for people with Type 1 diabetes or those who have really advanced diabetes where you really need that matching of the insulin with meals.

Sylvest: I was just wondering, before we talk about access and that you've talked about different groups of people having different types of problems getting the access. So, let's say we would get to provide any set of more affordable insulin, is there a way to avoid that or get clarity on that? We will not upset the system because of course that's one of the uncertainties that you say, you're not willing to and I'm not willing to have other people pay the price of me getting a better until in the future. The way the system is structured today, that might be if these subsidies are not there, the rebates, it might be other patients would be impacted by this. So that's one of the unknowns. I don't know if you have familiarity with the system that we would be able to get an overview of what could be potential effects of that. I'm just thinking to ask this point about what if it suddenly affects other types of patients? Would it be cancer patients or others?

Lipska: Yeah. If you get rid of rebates, are you asking, what is going to happen if you get rid of rebates? I don't know. And I've read mixed things about getting rid of rebates completely. It would potentially lower the list price, but there's no incentive per se if you removed the rebate for the list price to go down. So I think that the...

Jorgensen: You have my word, no, it's on tape, we're not going to keep the rebates. It will be passed on 100% or gotten rid of it. It would be passed through to the patient or we are simply lowering our price with that amount.

Holland: To come back to you [To Sylvest], Type 1 diabetics are tired of being asked to pay for other people. Because we are not being taken care of. And it's not fair. Watching people I know figuratively spending an arm and a leg, every dollar they have for insulin until they can't anymore and then they ration and 10 years down the line they literally lose an arm or leg and they go blind and they die a very undignified, painful and for the most part avoidable death.

And we're told over and over again that sacrifice is to keep other people alive. I'm tired of it. I don't want to hear it. I want to be taken care of. I want to know that I am going to live a long, healthy, full life. That I'm not going to be a financial burden on my partner, on my family. I don't want to be disabled. And I worked very hard for the last 22 years of my life to stay healthy enough to now have the opportunity to apply to medical school and people around me are too sick to do that. So I do understand where we fit in the system but it is unfair to ask us to pay to keep all these other people alive while this is what is happening to us.

Jorgensen: We are completely 100 percent on your side because, you know, the purpose of Novo Nordisk is to...

Lipska: ...keep people alive.

Jorgensen: Right, the change needed to defeat diabetes.

Holland: Yeah. Your mission statement you specifically state you serve a chronic population. It's inspiring and I am here personally, not as part of T1International, but just as a patient. As someone who uses Levemir when I take breaks from my pump. I prefer it to Lantus. It's a great product. I've used it for many years, I pay extra for it. That's how much I like it because it's not my preferred formulary.

So I am asking you how do we keep this going? How do I keep having this conversation with you and everyone else here, but really with you [to Jorgensen] to find solutions and to set deadlines. And to come up with concrete things, actions that we can work together that I can help inform. I want to continue talking to you and I want us to work together to improve this because I feel that the United States is hitting a health care crisis point.

There will be hearings coming up and when those happen I would love to be able to walk into that room and say, I've been working with this person in good faith and these are the things they have done that show me they're sincere and they're actually on our side making improvements. This is how things have gotten better. I can tell you Eli Lilly is not working with us or any patients in that way. Anytime one of my peers has met with them they have these nice conversations like we're having now and there is no follow up. There is no good faith effort. Nothing really changes. I would like this to be different.

Jorgensen: Yeah, me too. My dad has Type 2 diabetes, but he's not yet on insulin. So I don't live with the personal experience here. I don't live with the issue of managing a disease. But I work for a company with this mission and I live in a country where everyone has access. So we spent a lot of time understanding the U.S. health care system and I operate in say the business model that's there. I am frustrated by it because as you’re saying it's not solving society's expectations and when a company, an industry, is not solving society's expectations all kinds of bad things happen to that industry and those companies. So you have the industry, the companies, patients, politicians, physicians, nobody is pleased with the system as it is.

And so something will have to change that. When we make some changes it's my responsibility as the CEO of the company to make sure that we do it in a way where we are having a careful eye on what are the financial implications. Is it really benefiting the patients? So when there is change it has to solve the problem. We've committed to do our part and I would like to have the dialogue. And I really have to make sure that when we make these changes we do it in a way where it works in the system. Because you can make different programs and we have some, we have our full ability program, we have a Walmart offering, but they are not…they work for some, but they do not work for the majority.

So we need to do it in a way where we do it in collaboration with the PBMs. They welcome the initiative of course that the biggest guarantee is that it gets all the way through to the insurance company to the patient.

I don't want to talk about our competitors. I think different companies have done different methods so far. Each one of them costs a lot of money, but still we would like to do the change that actually solves the problem. So I believe I speak on behalf of all manufacturers that we see a dramatic erosion in the value of the market. Different companies tried to do affordability programs, cash programs authorized from regs. They all cost money.

But if they are not done in coordination with the other partners in the supply chain, it's a big risk that is not getting the impacts that it should with patients. So that's my conviction that we need to do something where we actually get through the supply chain.

As people look into the supply chain I think PBMs are also losing reputation. I'm surprised how well insurance companies can get away with not sharing rebates with the patients but not understanding maybe what they get out of it. I just don't know it...

Holland: That may change and there seems to be momentum for legislation to change it, but that still only helps people with insurance. That doesn't do anything for the uninsured and it does nothing for someone who may say, lost their job. Let's say I go work for a hospital company years down the line and that hospital group closes. I can Cobra it for a little while but very, very quickly I may be in a situation where I cannot afford to keep refilling my medication prescriptions and that's through no fault of my own. The other thing we see a lot in the States is the transition between childhood care and adult care, there have been recent studies, I'm sure you're familiar with them, where we see the DKA rate in America jumped between 18 and 26 as people are pushed off the insurance from their parents. We do not see that in Canada where insulin is available over the counter at an affordable price. So I think that is pretty telling.

I will also say, I know my organization says this - and I'm vocal about it too - yes, healthcare in the United States is very complicated but we do feel there is only one group that could end it tomorrow. And that's you. Because you could lower the price and we are asking you specifically to lower the price. And I understand it's complicated, we don't know all the ins and outs and we are speaking as a specific patient population kind of selfishly because we're watching our people die and this is survival for us now. This is not a, this would be nice…this is really life and death for myself and people around me. And yeah, I guess there's really no way around that. Just, we are specifically asking you to do that.

Jorgensen: We'll do what we can to help out. And, as I said, find a way where it's working within the system because if I just lowered the price and it means that we are off formulary, more patients would lose access than those for whom it works. Then you are of course saying, then I just switch to another product. Maybe they are okay, it would benefit those you represent, so maybe it's good. But there will be a significant smaller business for Novo Nordisk.

Lipska: But I think you can, I mean, you're not the only person in the hot seat, so to speak, in public opinion. Right? So you have the ability to speak with the PBMs or insurance companies and figure out how you can do that so that you don't lose your formulary placement. I think you're in a leadership position. It's not like nobody's going to use Novo insulin or something. So I think you can, right?

Jorgensen: Which is maybe something I do not fully comprehend not being American, but we can actually not discuss the list price with a PBM. So it's illegal for me to actually have a dialogue with a PBM around list price. So we cannot go to them and say if we lower our list price with, you know, whatever sentence, adapt the rebates so we are still on formulary. That's illegal because that's collusion. We were already sued in the US for colluding with PBMs and also for colluding with the manufacturers. So I hear what you're saying, but that specific discussion is illegal because that's a...

Lipska: Right and I'm not asking you to have a specific discussion. If I do this, will you do this? But you could get those...I don't know if you already have, but all of the stakeholders were at the congressional hearings. I think that there is a potential for figuring out a system, some system that will work a little bit better.

Jorgensen: So of course this is a certain thing we can discuss at the end of the day. It's also a matter of leading the way to doing something. The current mind is one where you are mixing free market with regulation. That's a very dangerous cocktail because, for instance, if you were on Medicare, the country’s sponsor program, we cannot help patients make products more affordable. If it's commercial health care we can. So there are a lot of things that we can and we cannot do which makes the current system locked up in a very painful way. So, I'm not here to complain about how business is going because we have good business.

Holland: Just to circle back. What's being done or what do you hope to do in the next year? How?

Jorgensen: So we're taking a deep look at what all our options are and how do they work in the system. How do we make sure that it actually ends up benefiting the patient? And we'll then have to decide which option do we go with.

Lipska: And what things are you considering?

Jorgensen: So if you look at what has been done. So, we tried to sell our products by a Walmart, so that's the route outside of insurance, that's a direct to patients. So what if we did more of that? Say an extreme, that we would have all products available there. Still it would not be over the counter because it's still modern insulin so you still need a prescription so maybe you can help lobby that. You know, it doesn't take a prescription that anyone can walk in by themselves. That's one that Lilly makes the authorized generic [inaudible] a little north of 50%.

Holland: Yeah, it's still very expensive.

Jorgensen: Yeah. And it's still not on formulary. So the PBMs today cannot take it on formulary. So it's difficult to get. Sanofi have this program where you can buy if you do not have insurance for $99.

You can get the insurance you need. So we're trying to look number one at those or find other ways where we can actually do something for enough patients, not just a few. I mean I'm here to listen, to understand the issues you are confronted with and try to understand what could help for you, what's the change you're looking for? We are in Washington tomorrow and we will meet some more people and then we have to make some decisions about what we do.

Hobbs: I'm interested in the Sanofi program specifically. What's your feedback from your patients and your constituents in regards to that? If a similar thing was done for rapid acting insulin,

LIpska: Remind me again, the $99 Sanofi program is only for people who have what kind of insurance or no insurance?

Hobbs: No insurance. It sounds like I could get a month supply even if it's several months for $100 of Novolog or Humalog or one of the rapid acting, would that be something that would help in the short term? In a situation where somebody is transferring between insurances.

Holland: Yes. It would be temporary. It still is quite a bit, but yes, of course. My three month list price through CVS is $1,600 for five vials. That's $320 list price for Humalog and I know Humalog and Novolog are so similarly priced, we can think of them as comparable. So $100 versus $1600. Yeah, of course. That's a huge help. But it's temporary and it doesn't help everyone.

Jorgensen: It's still complex to qualify for it.

Lipska: Right. And it's just the proliferation of the various plans. If you can imagine, as a physician, you're seeing patients and then you have to figure out, well, which one is this one? And I can never find the right solution for the patient in front of me. All of these sound great but then the patient comes in like, “oh no, in this situation, this doesn't work.” And my staff's time, a lot of their time, is spent figuring out where can we send this prescription so the patient can afford it? So again, this is why we keep coming back to the list price because, and I understand the complexity of it, but it's very hard to solve it within the current system, to plug up all the holes because there are so many different requirements. And so when you make it so complex it's not going to work well

Hobbs: I was just thinking how you would sit with patient eight or nine years ago and decide what rapid acting insulin they need and it's very different than...

Lipska: Than you do it. Now, ‘What is your insurance coverage?’ is the first question.

Hobbs: Before it used to be, ‘What one works best for you?’.

Lipska: It's completely driven by what's covered because when it's not covered, there's no way than most people can afford it.

Jorgensen: We are really trying to do our part but it's important that we also see simplification in the whole insurance area because that….

Holland: We'll work with you. We will. If that's a conversation more in depth you want to have. The problem we've run into is that...you haven't told me anything I didn't know already today when I walked in the door. We know it's complicated and we know the ways in which it's complicated because as patients we've had to navigate the system to stay alive. But we also want to see the system simplified. We want to know that you are a profitable business because you have no incentive to make a product if it is not profitable, but we want it to be reasonable both in cost to patients and in what those profit margins are.

And I find it really difficult when I look at earning reports year after year because what I see is that Humalog went from being a $3 million profit margin to a $3 billion profit margin. And when they then tell me, “oh, we're still losing money” or “the net price goes down,” I say I don't really, I don't know if I believe you. $3 billion and I'm paying every dollar I have for this and you're telling me it can't be cheaper is a very hard pill to swallow. We feel like we are really being squeezed here and that we want to just have lives that are meaningful and full

Jorgensen: No, I think that's completely fair. Thank you for your time. Thank you. It's a very motivating tool to listen to. And of course I read all the stuff also. Nobody can hide behind excuses. We need to do something. So thank you for giving the inspiration to me to keep pushing on that. And we will, as I said, we will try to do well part and I would encourage or welcome a dialogue again at a later point in time.

Holland: Is it possible for us to set up a follow up today? A time where we can check in or...

Jorgensen: I can promise you a follow-up. But I don't want to set a time on it today because we need to collect input and make up our mind sometime later this year.

Holland: Okay. Is it possible for me to get contact info? Can I give you my personal contacts?

Jorgensen: You can also have mine. Absolutely.