

Dear Mrs Davis,

Thank you for the opportunity to present a submission on Pharmac's proposal to enter a sole supply agreement with Pharmaco NZ Ltd for CareSens blood glucose meters.

This submission is presented on behalf of Diabetes Youth Wellington. We are a non-profit organisation made up primarily of parents and care givers of insulin dependent diabetics under the age of 18 and living within the greater Wellington region.

Firstly, we would like to acknowledge that we recognise the resources Pharmac puts into diabetes and are grateful for Pharmac's ongoing support. We would welcome any opportunity to work alongside Pharmac to reduce these costs.

But in proposing sole supply rights to the cheapest model of blood testing meter on the market for use by all diabetics – insulin dependent and non-insulin dependent – Pharmac is ignoring the greater risks of artificially injecting insulin over taking a pill and moderating your food intake and exercising more.

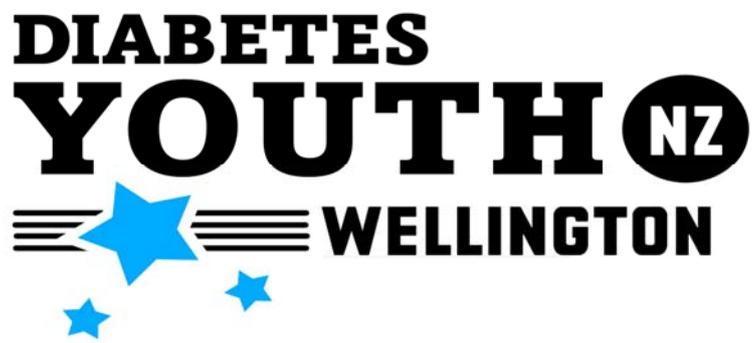
Type one diabetics – and the parents of young ones – are bombarded with messages to reduce their risk of contracting diabetes. Well meaning people suggest "cures" revolving around diet. So it appears the public can't differentiate between insulin dependent diabetes and non-insulin dependent. But Pharmac must.

Non-insulin dependent diabetics check their blood sugar levels to see how high they are. High blood sugar readings have long-term health ramifications. Among other things, high glucose levels causes the blood to thicken and it can't get to the extremities. Eyes, fingers and toes are particularly affected along with vital organs.

Insulin dependent diabetics check their blood sugar levels to see how low they are. Low blood sugar levels have short-term health ramifications. You die.

Our members see blood sugar meters as a tool that keeps their child alive.

The minutes from the Diabetes Subcommittee of PTAC meeting held on March 3rd, 2011 shows the subcommittee acknowledges that, on average, insulin dependent diabetics under test and non-insulin dependent diabetics over test. It goes on to say that over-testing is prevalent in rest homes.



It also notes that the HbA1c test is a more suitable measure of blood glucose levels in non-insulin dependent diabetics than blood testing.

So is the issue here the number of test strips non-insulin dependents are using? Is the sole supply agreement being brokered to reduce the cost of these test strips as their use grows with each diagnosis of diabetes?

Are insulin dependent diabetics being down-graded on a what they see as a life saving tool because non-insulin dependent diabetics, and their care givers, are overusing the same product despite there being a more reliable alternative?

It concerns us that just six months after that subcommittee meeting Pharmac entered into a provisional sole supplier agreement with Pharmaco to supply CareSens blood glucose meters and then, six months after that, informed the public of this decision and gave affected parties just three weeks to make submissions.

While we recognise the necessity of Pharmac to source the most cost-effective products, we disagree with the weight cost appears to be given in relation to this decision. We feel that not enough weight is being given to the potential health outcomes for young insulin- dependent diabetics.

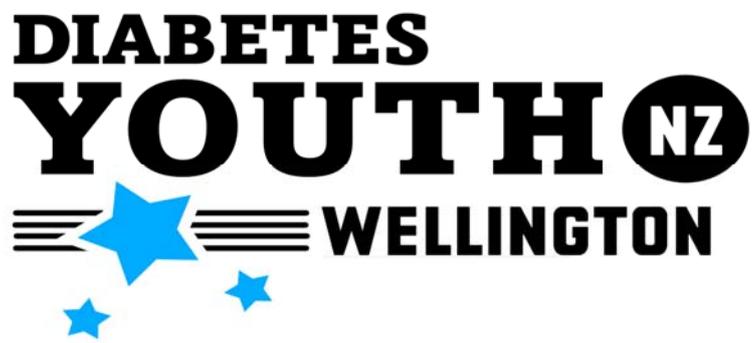
While Pharmac's consultation document acknowledges "a large number of patients" will be required to switch brands, it is our experience that all, or at least the vast majority, of patients will be required to switch. We are unaware of any young, insulin dependent diabetics using CareSens meters.

Pharmac also acknowledge that training will need to be provided to healthcare professionals and the need for them to pass on that training to diabetics and, in the case of young diabetics, their care givers.

But this acknowledgement misses the fact that further on-training will be required. Managing diabetes in a young person requires an entire network and that network may include teachers, siblings, friends, friend's parents, grandparents, baby sitters, neighbours, before and after school carers. In fact, anyone who may find themselves responsible for that child no matter how brief that responsibility is.

In addition to making sure everyone who may assist in the care of diabetes is aware of this change, all written instructions provided to schools, sports bodies, etc. will need to be rewritten, re-laminated and redistributed.

We accept that this could be seen as a short term issue but the possible result of any error being made during this changeover could be dire. To put it bluntly, an error in a blood glucose reading could be fatal.



We question the choice of CareSens as the sole provider. Having seen these meters for the first time at the public consultation meeting held in Wellington on Wednesday March 7th, they appear flimsy and are inferior to the ones we are currently using on every single feature that can be measured.

Firstly, the lancet pens, or finger-prickers, are manifestly inferior to those being used at present. They lack the fine control offered by other brands that allows the lancet to be set at half measures. This is very important for small fingers as care of the finger tips is crucial to diabetes management.

Enabling half-measure control when constantly taking blood samples from the tips of growing fingers allows for the least possible long term damage. In addition, anything that makes the process of introducing blood tests to a young child less threatening and 'scary' is of enormous benefit.

As an example, a child diagnosed with diabetes at the age of three was issued a lancet pen that was set to half and if it was ever moved above that she experienced pain. At the age of six, her lancet pen is still set to half.

It is often difficult to convey to a small child the importance of taking blood tests from as wide a variety of sites as is possible within already narrow confines. Even with utmost care, young diabetics fingertips often show damage from these constant tests and it is a concern that CareSens lancet pens will cause more damage and make teaching young diabetics safe practices more difficult.

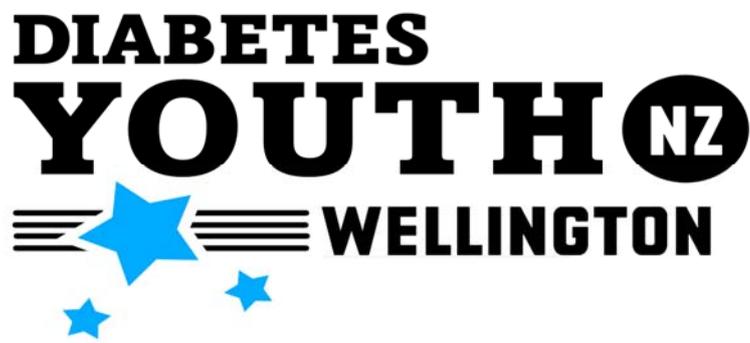
These lancet pens may suit adults but they are not suitable for small children. You need to consider how often this simple test is performed.

Using 75 as an average life expectancy, an adult diagnosed with non-insulin dependent diabetes at the age of 50 who tests once a day for the next 25 years will perform over 9,000 tests.

A child diagnosed with insulin dependent diabetes at the age of five will test around seven times a day for the next 70 years and will perform over 175,000 tests.

In this regard, one size does not fit all.

Another issue concerns both the lancet and the meter. Their cheapness is clearly seen as a positive in an economic sense but that cheapness will come at a cost to care of insulin dependent diabetics.



They do not appear sturdy enough to cope with the rigors imposed on them by being carried everywhere. They are certainly not going to cope with being thrown in a fit of pique and it needs to be noted that high blood glucose levels are recognised as causing mood swings.

Yes, that is an extreme example but they are thrown in bags and lugged around on the back. There appears to have been little in the way of field testing.

CareSens meters appear designed to be used occasionally by adults with non-insulin dependent diabetes. They are not suitable for those who require them to keep them alive, particularly children who are being encouraged to live as active a life as possible.

CareSens meters are also a backward step for those who are expecting the integration of pumps and meters. With the high numbers of diabetics worldwide and the advances being made in diabetic management the ability of the testing device and the dosage administering device to operate in tandem seems imminent.

It is strange timing for Pharmac to lock diabetics out of a technological advance that will improve their blood glucose management just as it is being rolled out.

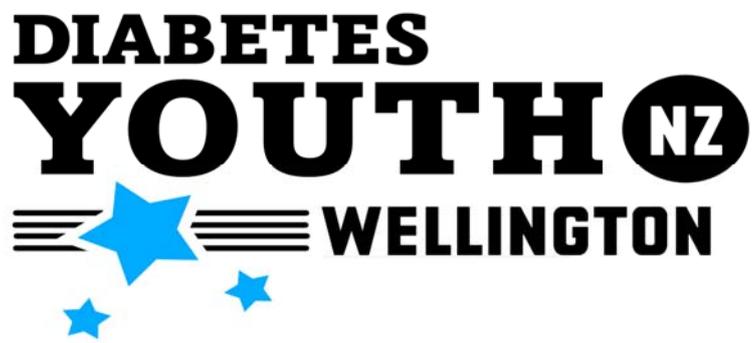
CareSens meters only provide a fortnightly average as opposed to other brands which offer 7, 14 and 30 day averages. Given that factors such as sickness, growth spurts, excitement, stress and exercise effect blood sugar levels, many of our members use the 7, 14 and 30 day averages to understand how these factors are impacting on their child's diabetes and adjust their care accordingly.

CareSens have smaller memories for tests, a lesser battery life (despite using two batteries instead of one as most other meters do), a reduced tolerance to temperature extremes compared to other meters and no backlight – an invaluable feature when performing night tests.

They are also only blood test meters so many diabetics will have to carry two meters with them. Keytone testing is an integral part of insulin dependent diabetes care and having one meter that tests both is seen as a boon by our members.

To summarise our concerns with the CareSens meter are:

- Too flimsy for the rigours of being carried everywhere
- Lancet pen without fine control
- a lesser battery life
- twice the number of batteries



- poor tolerance to temperature extremes
- no backlight
- small memory
- only 14 day average available
- cannot test keytones
- no ability to integrate with pumps

We recognise that offering sole supply is an effective way of getting the best price but this is primarily a health issue to us and the risks associated with putting all your eggs in one basket can't be over-stated. Should any natural disaster hit the site of manufacture or a shipping problem arise, how will meters and test strip supply be maintained?

And, while Pharmac may see it as just a three year deal that will be revisited after that time frame, the reality is that other providers will possibly leave the market affording Pharmaco Ltd a monopoly. What will be Pharmaco's motivation for providing best price in those circumstances?

And if, in three years' time, another provider is awarded sole supply status, we will need to go through this process all over again. The six year old mentioned earlier in this submission would have then started on one meter at three, switched to another at six, then switch to a third at nine.

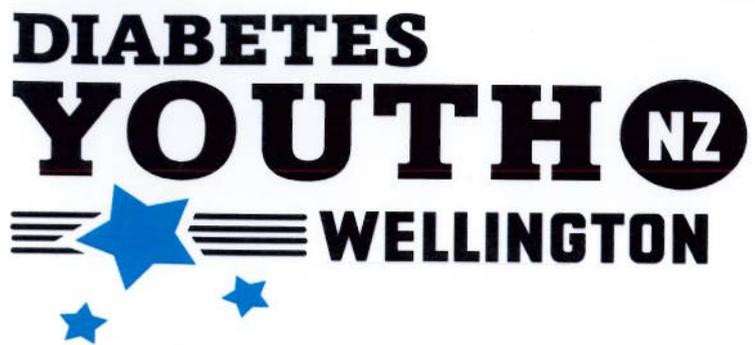
This was noted at the consultation meeting in Wellington on March 7th and the Pharmac representative said in response that diabetics change their meters regularly. While this may be true, these changes are always voluntary and, more importantly, they are never a down-grade.

We consider the needs of insulin dependent diabetics and non-insulin dependent diabetics sufficiently different to reject the one size fits all approach that Pharmac is taking and request Pharmac consider funding the two conditions separately.

We do not minimise the effects of non-insulin dependent diabetes but it needs to be recognised that as soon as you are injecting someone with insulin, you are introducing the risk of hypoglycaemic attacks and they can kill.

Anything that lessens the patient's (and their care givers) ability to monitor blood sugar levels needs to be carefully considered and the weighting cannot all be towards the costs.

DIABETES YOUTH NZ WELLINGTON



DYW believes the increased use in test strips is due to overuse by non-insulin dependent diabetics and feel we are being given an inferior product despite using them as life saving devices.

We are pleased to be able to contribute to this decision but note that it is six months since the provisional contract was signed. Presumably, there was an extensive quotation process and comprehensive decision making going on for some months prior to that.

Yet we – the very people who rely on a blood meter as a life saving tool – are given only three weeks to make a submission. And we, in Wellington, only saw the meters for the first time seven days before these submissions close.

We also feel we are not being given a great deal of information here. We don't know:

- what conditions need to be met before the contract goes unconditional
- when the contract goes unconditional
- what the suppliers were asked to provide in the quotation process
- whether any factor other than money was given any consideration
- if the meters have been field tested
- whether or not there is any possibility of this decision being reversed.

Pharmac needs to consider funding at least one other option of blood test meter for insulin dependent diabetics. Pharmac must not consider treatment of insulin dependent and non-insulin dependent diabetes as interchangeable. The risks of that approach are too great.

Thank you again for the opportunity to express our views on this proposed change in the delivery of this vital tool in the management of insulin dependent diabetes. We trust Pharmac will give our submission and all the other submissions you receive careful consideration.

Yours sincerely,



Rex Nairn
Secretary, Diabetes Youth Wellington committee