



Advocating for people with type 1 diabetes around the world

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Date: May 20, 2021

To: Secretary of the Expert Committee, Dr Benedikt Huttner

From: T1International and advocates living with diabetes from around the world

Re: Application to add (ultra-)long-acting insulin analogues to the WHO Model List of Essential Medicines

Dr Benedikt Huttner and the Expert Committee on the Selection and Use of Essential Medicines:

It is now well known that analogue insulin is estimated to cost approximately [\\$6 per vial](#) to produce. There is no reason that this essential hormone should not be available at a reasonable price for anyone worldwide who needs it. Access to insulin is a human right, and an Essential Medicines List (EML) where only the 'bottom tier' of insulins is deemed essential is not acceptable. Not including analogue insulin on the EML creates a two-tiered system where the wealthy get access to the best forms of treatment and the poor either go without or suffer with [less effective insulin](#) which results in [poorer quality of life](#).

Analogue insulin has primarily been the insulin of choice for people with type 1 diabetes in high-income countries for many years. Regular insulin works slower and does not allow for flexible dosing around varying amounts of carbohydrates and eating schedules. NPH necessitates an additional injection daily and has an intense peak of action that puts people with diabetes at a higher risk of low blood sugar and makes them dependent on a rigid eating schedule. This is particularly difficult to achieve in some of the most remote and rural parts of the world where regular access to medicine and healthcare is often an overwhelming challenge.

Analogue insulin allows for the use of insulin pump technology, more flexible diets and eating schedules, eating around faith events like Ramadan and others, lower risk and fear of hypoglycemia, and overall improved quality of life. It is an injustice that people in high-income countries can expect access to the most effective and health-promoting insulins available, while people in low- and middle-income countries do not benefit from the same access. *T1International believes firmly that long-acting Analogue insulin must be added to the WHO list of essential medicines.* We would like to see rapid-acting insulins such as Humalog added to the EML as well, but these are not up for consideration this cycle.

In 2019, "The Committee noted the long-standing domination of the insulin market by three manufacturers, limiting broader competition and slowing the entry of biosimilars to the market. Recognizing the complexities of these problems and the need for a wider understanding of the insulin market and access to insulin, the Committee recommended WHO coordinate a series of actions to address the issues of insulin access and affordability. In the absence of other coordinated actions, the Committee considered that the inclusion of insulin analogues for adults on the EML would be inadequate to address the underlying issues of poor access and affordability of insulins more generally."

The WHO justifying inaction by saying it will not be adequate fails to address the issue of manufacturer monopolies and price-gouging. To see a world health leader taking this stance is extremely disheartening. Not to mention, civil society groups, including T1International, *have* coordinated actions to address the root causes of the issue. If the application is rejected for a third time, the diabetes community will continue to feel that the voices of people with diabetes do not matter and that the WHO is not listening to those who live this reality every day.



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**Below T1International shares additional insights from our community of advocates living with diabetes.**

I can still remember the day I got to change from NPH insulin to analogue insulin. It made a difference of night and day in my life. My allergies went away, my hypoglycemic episodes reduced significantly, and most of all it made me feel safe in my own skin. I have been paying out of my own pocket for analogue insulin for years because my healthcare system did not provide it. Things are starting to change now, but we still have a long way to go. I am well aware that paying for them is not a possibility for most people in my country. I am always making sure I handle my money properly so I can afford to buy them, and the thought of having to go back worries me a lot. I believe everyone with diabetes should have access to analogues. They are not only the treatment that keeps us alive, but also one that gives us quality of life, something I believe we all deserve.

**- Daniela Rojas, Costa Rica; Age 38, 29 years with diabetes, Insulin Pump Therapy with Humalog**

Analogue insulins should not cost that much. They are not much more complicated to produce than human insulins. Serious research has shown that it would be possible to price a 10mL 1000 unit vial of glargine (Lantus) at less than \$8 and still make a profit. Glargine has been around for 20 years now and it is not covered by any patent anymore. It should be available to anyone who needs it, and it is high time WHO made this happen!

**- Frédérique Georges-Pichot, France; Age 41, 12 years with diabetes, Humalog and Lantus**

I have lived most of my life with diabetes using mixtard (human insulin). The main challenges I had with it were the very frequent lows that forced me to eat. This affected my HbA1c. When I was pregnant, I had to change back to human insulin after using analogues because I couldn't afford anything else. Due to this, I had several instances of dangerous hypoglycaemia that led me to lose consciousness and need to go to the hospital. Now, using the analogues, I know that it gives room for easy insulin adjustments, taking it as and when I have a meal. I feel more in control of my diabetes and my HbA1c is better. I believe that is the ultimate goal of every diabetic. Hence why analogues should be part of the essential medicines list.

**- Yaa Bimbeh, Ghana; Age 32, 19 years with diabetes, Novolog and Lantus**

I would be devastated if I had to use NPH insulin, as it has many flaws in the way it acts and it would affect my sugar levels drastically. Lantus is the pillar that is keeping me alive and healthy, so I would like to request WHO to add Long acting insulin (Lantus and Tresiba) to it's Essential Medicine List (EML).

**- Mohammad Omer Alam, Pakistan; Age 21, 10 years with diabetes, Apidra and Lantus**

I'm not satisfied with NPH at all. It shows awful results, like sudden highs or sudden lows. The peaks from NPH insulin are like a nightmare for me. There's no flexibility in using NPH. As I'm Muslim, I do fasts during the month of Ramadan and that is not suitable for me. When I was able to use Lantus, I found it to have been life-changing, giving me much flexibility with my meal routines or lifestyle. I only needed to use it once a day and did not observe many peaks. If I could use and have access to long acting insulin analogues, my life would definitely be more smooth and less scary compared to when I use NPH.

**- Sobia Aziz Siddiqui, Pakistan; Age 28, 10 years with diabetes, Humulin 70/30 and Actrapid**

If I had to use only NPH insulin, I would be upset that my prescription options were being determined by price and not medical necessity.

**- Eli Terris, United States; Age 33, 2 years with diabetes, Lantus and Humalog**



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I used Pork and Beef insulin when I was diagnosed, then went to NPH and Regular when it was new, and have been between Humalog and Novolog for over 20 years. I can honestly say there is a night and day difference in the control between human and analogue insulin. NPH is and always has been a roller coaster insulin for blood sugars, which is far more dangerous to the long-term health of a person with diabetes. In the long run, both money and lives would be lost with the amount of people who would go into diabetic ketoacidosis (DKA) if they remained on human insulins.

**- Brittany O'Donnell, United States; Age 32; 31 years with diabetes, Insulin Pump Therapy with Novolog and Lantus for backup**

If my endocrinologist told me that they were switching me to NPH insulin because the cost of production of my current long-acting insulin was too high, I would be afraid for my life. After being diabetic for 13 years, even the more effective analogue insulins stop working as well in my body and I have to try other analogue insulins so I don't risk DKA or unhealthy A1Cs. Going onto NPH would severely endanger my life and would not be adequate enough to keep up with my body and maintain my health.

**- Jessica Allston, United States; Age 20, 13 years with diabetes, Fiasp (after becoming resistant to Humalog)**

When I was in the hospital for appendicitis, they had to do emergency surgery and told me to remove my pump. My mom and I requested that I be given Lantus since I had been on it when first diagnosed and knew how it worked in my body, including during sick days. The anesthesiologist and surgeon refused and gave me NPH instead. In post-op, I was severely low and continued that way throughout the rest of the night. My mom was up manually checking my blood sugars and making me drink cranberry juice until they finally gave me a dextrose drip. It is scary to think others would be forced to rely on NPH, which has been proven to be outdated and less effective for diabetes management.

**- Claire Clendenen, United States; Age 26, 14 years with diabetes, Insulin Pump Therapy with Humalog and Lantus for backup**

If I had to use only NPH insulin, I would feel disadvantaged and cheated in my healthcare. I have gone years of switching insulins/ratios to finally get my 6.6 A1c. Not all bodies react the same, and we have to take the proper care. If we are not given that option, we are being limited to caring for ourselves in the best possible way our bodies need. We deserve that right and that life. Remember, insulin was a gift to mankind.

**- Franee Mills, United States; Age 31 years old, 6 years with diabetes, Novolog, Tresiba, NPH**

I am a physician with difficult shifts and hours. The flexibility of long-acting insulin with no peak allows me to safely meet my job's demands. The peak of NPH requires meals at preset times to avoid hypoglycemia. It also causes a significant increase in overnight hypoglycemia. Being on NPH would limit me substantially and affect my livelihood, health, and well being.

**- Kathryn Nagel, United States; Age 30, 20 years with diabetes, Tresiba and Novolog**

When I was first diagnosed with type 1 diabetes, I was started on NPH. It was jarring to go from eating how much I wanted, when I wanted, to suddenly being on a very regimented, time-specific diet. As a high schooler, it was almost impossible to maintain this schedule and it reflected in my erratic blood sugars, including scary low blood sugars. All people with diabetes should have access to the insulins that are best for their needs, regardless of price.

**- Kristen Whitney Daniels, United States; Age 30, 15 years with diabetes, Lyumjev and Toujeo**



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If I had only one option for the type of insulin I could use, I wouldn't be a happy patient considering it's my life and somebody else is trying to capitalize on a necessity. It's very disappointing knowing some company has control over how I live my life.

**- Samuel Baker, United States; Age 27, 18 years with diabetes, Basaglar and Humalog**

If I had to use human insulins instead of analogues, I would lose a lot of flexibility to live more freely. I would be really concerned about the danger of having severe hypoglycemia or developing diabetes complications because of the unpredictability of human insulin action. My mental health would be under a lot of stress and fear. Life would be very difficult and stressful.

**- Angélica Luna, United States; Age 31, 20 years with diabetes, Lantus and Humalog**

If I had to use only NPH insulin, I would be at a complete loss. I used Lantus for the first 13 years of my life with type 1 diabetes, and have only found better control since switching to Tresiba and Apidra. It would be utterly devastating to my quality of life if I were required to use NPH rather than analogues.

**- Megan Johnson, United States; Age 33, 15 years with diabetes, Apidra and Tresiba**

I am currently using an insulin pump with Humalog. I eat constantly as I'm active in 3 sports. Having to use human insulin would so limit my life. Juggling insulin injections with exercise is already complicated and I can't imagine how limited my life would be without my analogue insulin.

**- Vince Giulian, United States; Age 18, 6 years with diabetes, Insulin Pump Therapy with Humalog**

If I did not have analogues I know I would need to adjust my eating habits and schedule which is nearly impossible to do as a nursing student who works multiple jobs. One of those jobs, as a registered nurse, does not follow a strict schedule for eating while on the job. I can only imagine that my current lifestyle with school and work will not be fit for my own diabetes management with NPH and regular insulin. My diabetes management would fall apart.

**- Katarina Yabut, United States; Age 28, 23 years with diabetes, Insulin Pump Therapy with Humalog**

I was on NPH after diagnosis at age 6, and again after grad school when my pump died and I had no backup long-acting insulin, or insurance to pay for Lantus. NPH had just come off patent so I was able to buy it for cheap and without an RX. I would never choose to use NPH due to its unpredictable mechanism of action.

**- Annette Chmielewski, United States; Age 36, 30 years with diabetes, Insulin Pump Therapy with Novolog**

Having to advocate for my own best care can be stressful and difficult. I couldn't imagine having a lesser insulin product forced on me due to cost, especially in modern times. Others should have access to the best care available.

**- Jeremy Goldkuhl, United States; Age 31, 2 years with diabetes, Tresiba and Humalog**

The lack of personal choices regarding insulin preferences makes me unhappy. Everyone should have access to analogues.

**- Dakota Disch, United States; Age 15, 7 years with diabetes, Insulin Pump Therapy with Humalog**



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I hope to see the WHO include modern insulin as an essential medication. Modern insulin analogues are absolutely essential to today's population of people with diabetes. I have developed a lifestyle and work schedule completely reliant on the flexibility of insulin analogues. I could not use NPH insulin without needing to limit my career and community involvement.

**- Caylan Fazio, United States; Age 24, 8 years with diabetes, Lantus and Novolog**

When my physician introduced me to analogue insulin a few years ago because of my hypo frequencies and depth, I didn't think I would see any significant change in my health. A few years down the line, I see myself as one of the luckiest people alive. The way my quality of life and health have improved because of analogue insulin is incomparable, I have experienced my best years with diabetes on analogue insulin than NPH. They truly are a gift to the diabetes world, one that everyone with diabetes deserves to experience!

**- Yemurai Machirori, Zimbabwe; Age 28, living with diabetes for 17 years, Tresiba and Novorapid**

#### **T1International Team Members**

I used R and NPH as a child and suffered from seizures due to rapid and unexpected drops in blood glucose levels. I had worse blood sugar control and a worse quality of life. I have seen the same things happening to people all over the world living with diabetes that have only one option for their insulin regime. I would be terrified if I was told I had to return to using those insulins after being on analogue insulin, and it is unacceptable that this decades-old form of insulin is not deemed essential.

**- Elizabeth Pfister, United Kingdom, Executive Director; Age 33, 29 years with diabetes, Insulin Pump Therapy with Humalog and Lantus for backup**

Immediately upon diagnosis and for many years following, I used R and NPH insulin. For several years, I thought it was "normal" to experience violent lows which affected my ability to participate in school, activities with my peers, and experience a healthy childhood. I can still remember the marked change in quality of life when I began using Lantus analogue insulin as a teenager. Many years later, I was temporarily forced to use NPH again after a change in insurance. The fear I experienced, of once again relying on an unreliable treatment, is hard to put into words and is a situation no one should be subject to, especially so many years after analogue insulins were introduced.

**- Kate Pidwerbecki, United States, Operations Manager; Age 30, 20 years with diabetes, Insulin Pump Therapy with Humalog and Lantus for backup**

If I were told that I had to use NPH insulin I would be outraged. My family members would be outraged. My friends in my diabetes support group would be in disbelief. Being switched from my current long-acting analogue insulin, Tresiba, to NPH would severely limit my life. In the diabetes community we talk about diabetes not holding us back from living the life we want or from living a normal life. Yet, there is nothing normal about having to eat on a fixed schedule or facing a severe low blood sugar, or about having to accept a sub-par therapy that does not facilitate optimal blood glucose control. There is no way I could have the job and the independence I have now if I was on a fixed insulin regimen. NPH insulin would keep me alive, but it would take away my quality of life.

**- Katie Souris, United States, Global Advocacy Consultant; Age 33, 16 years with diabetes, Novolog and Tresiba**