

Testimony - Marina Tsaplina
May 28, 2019 Public Hearing - New York Health Act
Albany, NY

[shortened version - 5 minutes]

My name is Marina Tsaplina. As I speak I hold in my consciousness the people whose lives our senseless health system has taken. I live in Brooklyn, NY. My mother, who is here today, lives in Staten Island.

I testify to make visible the structural violence that this health system inflicts on the bodies of people with diabetes, clinicians and families. I testify to the moral failing at the root of our health crisis, one that I have witnessed and participated in when leading an industry-supported patient advocacy organization. I testify to stop the growth of evil by calling it by its name and taking responsibility for my role in it.

I was diagnosed with type 1 diabetes in the Soviet Union in 1988. I was two years old. My family moved to the U.S. largely because of my illness, driven by a dream of America, a hunger for a politics of integrity, and a belief that I would have the best chance to flourish here.

Yet here I am, uninsured.

Diabetes was fatal until the discovery of insulin in 1921. Its patent was sold for \$1, as its discoverers believed it was unethical to profit off of a life saving drug.

Yet I cannot afford my medicine.

Drop the word 'care' from this health system. This system is organized around neglect. There is no such thing as a preexisting condition – it was made up to deny care. Being insured is often no better than being uninsured, and this structural neglect is violence. Amputation rates for people with diabetes between the ages of 18 to 44 have increased after two decades of steady decline due to the instability and unaffordability of both health coverage and medicine. Despite vocal commitment to medical innovation and claims to universal health coverage, the first great breakthrough in modern medicine is today the 6th most expensive liquid in the world, and I have not had a doctors appointment in five years.

Call evil by its name!

This system of neglect is the result of a great moral failing that is captured in this phrase: "prices should reflect the therapeutic value of medicine & positive outcomes to society."

It sounds innocent. But the therapeutic value of insulin is my life. Pharmaceutical and health insurance market, what is the price of my body that needs insulin, regular check ups on my internal organs, and a stable relationship with my clinician? Tell me the price of my body. Or does that question summon the ghosts of America's past?

The cost of a health system guided by unrestrained profit and the illusion of choice is paid for by the loss of feet, eyes, kidneys, hands, husbands, mothers, wives, fathers, sisters, brothers, and children- in Kentucky a son was taken from his family because they could not afford his diabetes supplies- clinicians, nurses, and doctors, who have the highest suicide rate of any profession due to moral injury. The trust fundamental to the therapeutic relationship between clinician and patient cannot survive in a system that holds the bottom line above the relationship. This perversion shatters the bedrock of health care. Care cannot survive here.

Evil grows where men and women are willing to sacrifice truth on the altars of their self interest and we must never forget, said the great Martin Luther King Jr, that evil never voluntarily relinquishes its throne.

I call evil by its name and I claim my role in it. My organization focused on the psychosocial and mental health aspects of living with chronic illness, and I accepted \$40,000 from the pharmaceutical industry to support its work. Was evil in my fingers when I hesitated to write publicly about the ravishing price of insulin for fear of not being funded in the future? Was evil in the words of the new CEO of JDRF, the global type 1 diabetes charity, when he told me 'Pharma is taking advantage of a corrupt healthcare system" but did not directly say that it is a driver of corruption with its patent abuse and the death of Alec Raeshawn Smith? Was evil in the silence of a group of patient advocates who, when the hashtag #PatientsOverProfits was rejected in an industry-supported diabetes advocacy campaign, said nothing?

All that the growth of evil requires are small daily violations by the hands of many good people. How this system is currently organized is incapable of bringing good care to the majority of the people in this state and country, and for this reason I call on this body to bring the New York Health Act into law.

[full version - 10 minutes]

My name is Marina Tsaplina. I speak before you today holding in my consciousness the people- both known and unknown- whose lives our senseless health system has taken. I live in Brooklyn, NY with my fiancé Miguel. My mother, also Marina, lives in Staten Island.

I testify to make visible the structural violence that this health system inflicts on the bodies of people with diabetes, clinicians and families. I testify to the moral failing at the root of our health crisis, one that I have witnessed and participated in when leading an industry-supported patient advocacy organization. I testify to stop the growth of evil by calling it by its name and taking responsibility for my role in it.

I was diagnosed with type 1 diabetes in 1988, when I was two years old, in the former Soviet Union. My mothers friends would ship us diabetes supplies from America because so little was available in Russia at the time. In 1991, my chronic illness fueled my family's decision to uproot their lives and arrive on this shore, driven by a dream of America, a hunger for a politics of truth and integrity, and a belief that I will have the best chance to flourish here.

And yet I stand here before you today uninsured.

Diabetes is one of the most studied diseases in the history of medicine, its first mentions trace back to a collection of ancient Egyptian medical texts, written on papyrus around 1552 BC. Type 1 diabetes was fatal, treated with starvation

diets and slow and painful deaths, until the discovery of insulin in 1921. Its discovery was the first significant breakthrough in modern medicine, transforming the once fatal disease into a chronic condition. The patent of the medicine was sold for \$1, as its discoverers believed it was unethical to profit off of a life saving drug.

And yet I stand here before you today unable to afford my medicine.

I can tell you that insulin costs about \$6 to manufacture, that in 1996 a vial of Humalog insulin cost \$21 and in January of this year that same vial cost over \$300. That its maker, Eli Lilly, in a public relations stunt released its own generic version of the drug last month that is to be sold only in the United States for around \$140 per vial. But 3 weeks ago in France, I bought the original nongeneric Eli Lilly insulin over the counter for \$36 USD.

I tell you these numbers but you have heard them before.

Drop the word 'care' from this health system for this system is organized around neglect. There is no such thing as a preexisting condition – that term was made up to deny care. Being insured is often no better than being uninsured, and this structural neglect is violence carried on the bodies of people in my community. Amputation rates for people with diabetes between the ages of 18 to 44 have increased after two decades of steady decline due to the instability and unaffordability of both health coverage and medicine. Despite vocal commitment to medical innovation and claims to belief in universal health coverage, the first great breakthrough in modern medicine is today the 6th most expensive liquid in the world, I have not had a doctors appointment in five years, and according to a 2018 Yale study, 1 in 4 patients are dangerously rationing insulin due to its cost.

This structural violence of neglect results from having abandoned ones ethical duties and responsibilities in favor of personal gain.

The cost of a health system guided by unrestrained profit and the illusion of choice is paid for by the loss of feet, kidneys, eyes, hearts, lungs, hands, husbands, wives, fathers, mothers, nieces, sisters, sons- in Kentucky a son was taken from his family because they could not afford his diabetes supplies- daughters, brothers, clinicians, nurses, therapists, and doctors, who have the highest suicide rate of any profession due to moral injury. The trust fundamental to the therapeutic relationship between clinician and patient cannot survive in a system that holds the bottom line above the relationship. This perversion shatters the bedrock of health care. Care cannot survive here.

Of course the economics of healthcare matter, but the financial analysis of the New York Health Act has been done, both by UMass/Amherst Economics Department Chair, Gerald Friedman and by the RAND corporation. Both agree that the New York Health Act is fiscally responsible, and that it will save money - up to \$45 billion in net savings to families, businesses, and taxpayers.

The issue here is not about economic feasibility. If it was, you would not continue to allow the pharmaceutical and private insurance industries to ravage us and impoverish our communities. The issue is the difficulty of standing up to the tremendous power of certain groups who hold hide their self-interest behind an unwavering faith in a free market at the expense of our lives.

This system of neglect is the result of a great moral failing that is captured in this phrase: "prices should reflect the therapeutic value of medicine & positive outcomes to society." It sounds innocent, but this sentence reveals the logic

rampant in the health policies that are destroying us. That sentence was written on May 25, 2019 by the International Federation of Pharmaceutical Manufacturers and Associations in a global meeting at the World Health Assembly gathered to draft a global drug pricing transparency resolution.

That sentence is a moral failing because the therapeutic value of insulin is my life. So tell me, pharmaceutical and insurance market, what do you deem to be the price of my body that needs insulin, regular check ups on my internal organs, and a stable relationship with my clinician? Tell me the price of my body. Or is that question chilling? Haunting? Perhaps it summons the ghosts of America's past?

For a virtuous practice of healthcare and medicine cannot be guided by a market that has no constraints. Evil grows where men and women are willing to sacrifice truth on the altars of their self interest and we must never forget, said the great Martin Luther King Jr, that evil never voluntarily relinquishes its throne.

And I am not innocent here. I call evil by its name and I claim my role in it. My organization focused on the psychosocial and mental health aspects of living with chronic illness, and I accepted \$40,000 from the pharmaceutical industry to support its work. Was evil in my fingers when I hesitated to write publicly about the ravishing price of insulin for fear of not being funded in the future? Was evil in the words of the new CEO of JDRF, the leading type 1 diabetes charity, when he told me 'Pharma is taking advantage of a corrupt healthcare system" but did not directly say that it is a driver of corruption with its patent abuse and the death of Alec Raeshawn Smith? Was evil in the silence of a group of patient advocates who, when the hashtag #PatientsOverProfits was rejected in an industry-supported diabetes advocacy campaign, said nothing?

In the fall of 2017, I was invited to a gala in Washington D.C. for the PhRMA foundation where I was personally introduced to Stephen Ubl, the top lobbyist in the United States for the pharmaceutical industry. The introduction was made with the thought that the PhRMA foundation could potentially fund some of my organizations work. I stared into the eyes of this man. Is this the face of evil? I asked myself. No, I answered. But then where is it? He has a daughter with type 1 diabetes and yet has been reported to say behind closed doors that the price of insulin should be higher.

As I released his gaze I understood that it was my humanity that was on the line, that I am small and the sphere of my actions tiny, but my hands will not aid those deeds. And with that choice, I released my will.

All that the growth of evil requires are small daily violations by the hands of many good people. How this system is currently organized is incapable of bringing good care to the majority of the people in this state and country. My chronic illness is not a tragedy, nor is it a charity. It is not a space for your pity, nor is it something to be conquered and overcome. The fact of my chronic illness demands one thing and one thing only: interdependence because illness is a part of life. And it is on the ground of mutuality that I call on this body to bring the New York Health Act into law.

DIABETES COSTS AND COMPLICATIONS

Resurgence of Diabetes-Related Nontraumatic Lower Extremity Amputation in the Young and Middle-Aged Adult U.S. Population

<http://care.diabetesjournals.org/content/early/2018/11/05/dc18-1380>

The Incidence of Diabetic Ketoacidosis During “Emerging Adulthood” in the USA and Canada: a Population-Based Study

<https://link.springer.com/article/10.1007/s11606-019-05006-6>

One in four patients say they've skimped on insulin because of high cost

<https://news.yale.edu/2018/12/03/one-four-patients-say-theyve-skimped-insulin-because-high-cost>

T1International Patient Survey. Useful tools for comparing cost in America to other countries:

<https://www.t1international.com/insulin-and-supply-survey/>

Among Low-Income Respondents With Diabetes, High-Deductible Versus No-Deductible Insurance Sharply Reduces Medical Service Use

<http://care.diabetesjournals.org/content/40/2/239>

Changes Over Time in High Out-of-Pocket Health Care Burden in U.S. Adults With Diabetes, 2001–2011

<http://care.diabetesjournals.org/content/37/6/1629>

A Lack of Decline in Major Nontraumatic Amputations in Texas: Contemporary Trends, Risk Factor Associations, and Impact of Revascularization

<http://care.diabetesjournals.org/content/42/6/1061>

MORAL INJURY

Beyond burnout: The real problem facing doctors is moral injury

<https://www.medicaleconomics.com/med-ec-blog/beyond-burnout-real-problem-facing-doctors-moral-injury>

How Healthcare Is Causing 'Moral Injury' to Doctors

<https://www.medscape.com/viewarticle/910309>

The Challenge of Competing Binds: Reframing Burnout in the Context of Moral Injury

<http://www.nhms.org/challenge-competing-binds-reframing-burnout-context-moral-injury>

Physicians to Administration: Stay Out of Doctor-Patient Relationship

<https://www.aafp.org/news/opinion/20180523prezmsgtitlex.html>

WORLD HEALTH ASSEMBLY TRANSPARENCY RESOLUTION

"[drug] prices should reflect the therapeutic value of medicine & positive outcomes to society"

https://twitter.com/jamie_love/status/1132329574673649668?s=20

WHO publishes May 22 version of transparency resolution with 110 brackets. We compare to original proposal.

<https://www.keionline.org/30823>

Monday v Wed draft of transparency resolution

https://docs.google.com/document/d/1XV606T7M6E40REOUgkMkxTi1Nyf4376eXqPa_bKCAV0/edit

Marina Tsaplina - Testimony May 29 2019 - Albany, NY - New York Health Act Public Hearing

Medicine Prices: Secrecy-Of-R&D-Costs Remains Issue In Near-Final World Health Assembly Resolution

<https://www.healthpolicy-watch.org/medicines-prices-secrecy-of-rd-costs-remains-issue-in-nearly-final-wha-resolution/>