

Gaslit Nation Transcript

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Special Episode, "Save Baby Dima: A Story of Hope From Ukraine"

<https://www.patreon.com/posts/save-baby-dima-50983551>

Andrea Chalupa:

Welcome to Gaslit Nation. My name is Andrea Chalupa, I am a journalist and filmmaker, and the writer and producer of the journalistic thriller Mr. Jones, about Stalin's genocide famine in Ukraine.

Andrea Chalupa:

As Secretary of State Antony Blinken visits Ukraine this week, showing American support for its long time ally as Putin continues to ramp up aggression against Ukraine, including 80,000 troops on the border—they are still there—in what looks to be a possible escalation of Russia's ongoing invasion, I wanted to highlight a hopeful story from Ukraine. So I'm interviewing an old friend, the Ukrainian civic leader, Olya Yarychkivska, a co-founder of Razom, a nonprofit organization with an impressive international network of volunteers who develop civic engagement and anti-corruption efforts for Ukraine. Olya is also a PhD in genetics and a postdoctoral fellow at Rockefeller University. Welcome to the show.

Olya Yarychkivska:

Hi Andrea. Thank you so much for having me today.

Andrea Chalupa:

I'm thrilled, so lots to talk about. First off, what do you make of Ukraine being so prominent in the news these days, especially for Americans?

Olya Yarychkivska:

Well, it's obvious that a lot of things are happening around Ukraine as Putin is trying to escalate the situation again, bringing the troops to the border. I am very happy to see that Blinken is in Ukraine right now. It's a strong show of support. We really hope for continual support from the US because parts of Ukraine have been taken away already and thus, we are at hybrid war that nobody can understand how to deal with. And we just really hope that US and other countries, other world leaders, won't allow further dismantling of our country.

Andrea Chalupa:

What do you hope Blinken will accomplish during his visit to Kyiv?

Olya Yarychkivska:

Well, I really hope that this will be a strong message to Putin to de-escalate and essentially to show that the US is backing Ukraine and that if he tries to go any farther, there will be consequences.

Andrea Chalupa:

And what do you make of Putin's recent escalations?

Olya Yarychkivska:

I think he always tries to distract from the internal problems that are taking place in Russia. This is a big distraction for Russian people themselves. So I'm not quite sure what to tie it to, but this is my feeling. And I guess we will see in retrospect.

Andrea Chalupa:

And so overall, there's been over 13,000 people killed in Putin's war and roughly 7% of the country of Ukraine is under Russian occupation.

Olya Yarychkivska:

Yes. It has been a tough, but also hopeful period of Ukrainian history since the Revolution of Dignity, since Euromaidan protests, and today I'm very excited to talk about my project because it actually brought together all of those activists that were super active during the Revolution of Dignity and all of the civic leaders to accomplish something different, and I believe something that will further continue change in Ukraine for the better.

Andrea Chalupa:

Yes, and we're going to be talking about baby Dima. Dima is an adorable, little baby. He's just a couple of months old and he was born to a prominent Ukrainian civic leader who represents the future of the country but, unfortunately, Dima was born with a genetic issue and this is how you and I connected over this story. You shared a GoFundMe link about Dima's story that broke my heart and I shared it widely on Twitter and other people I hardly ever hear from DM'd me to share how heartbroken they were of Dima's story, because the GoFundMe is trying to raise an astronomical amount of money to get the world's most expensive gene... the most expensive treatment period from a major pharmaceutical company. And it's just this race against time, because Dima must receive this treatment soon or else he could die.

Andrea Chalupa:

I called you up panicked over Dima's story and you shared with me such uplifting information about this larger campaign that you and others at Razom launched to try to save Dima's life. Instead of just saying, "Oh, it's just one baby. They'll have another baby," you really focused on the fragility of life and why every life matters. It's such a beautiful story. So could you share with us this campaign, this race against time that you've been organizing and leading, and why it matters?

Olya Yarychkivska:

Yes, I really think it's an incredible story because it's a story of a single baby whom we're trying to save that will essentially bring about the whole change of status quo of how these kids with this genetic condition are treated in Ukraine. But on top of that, there is another layer. This baby brought together all of the civic activists and leaders from the Revolution of Dignity, because his father was a huge leader during that time and he was a key person, the head of the self-defense unit, who prevented the Russian takeover of Odessa. Actually, it was May 2nd, 2014, so we're around this time. So, it's quite incredible.

Olya Yarychkivska:

And I think that bigger projects will come out of this. We are uniting all of these civic leaders, and first thing that we want to accomplish, of course, is to help baby Dima, but also we found all the other kids who are suffering from this disease at various stages. This disease actually can happen in several types. Baby Dima has the worst type, it's type one. It's essentially, you die by two years of age if you are not

treated. There is a second type, third type, fourth, adult onset type. There are all of these kids, but a lot of them are wheelchair bound, a lot of them die young, and live a really harsh life. So we are hoping to help all of them.

Olya Yarychkivska:

So we organized this advocacy campaign called 'Life for SMA Kids' where we are advocating for Ukrainian government to start a real SMA program that would fund the treatment, rehabilitation and genetic screening and everything that's necessary to essentially detect this disease in newborns, treat it early and have these kids live a normal life.

Olya Yarychkivska:

So the thing with this disease is that it's a progressive neurodegenerative disease and essentially, the earlier you treat it, these kids can really be like normal people. We connected with some families in the US and read some amazing stories online, because most of the states in the US do this genetic screening. You detect this in the newborn. You treat the baby before any symptoms are shown. We talked to a family with a three year old, and this boy is just running around doing normal things like any other child. So this is quite incredible, and it's really amazing that for this rare genetic disease, which is actually number one killer of young kids, there is this revolutionary treatment.

Olya Yarychkivska:

It's just really sad that in Ukraine, there are all of these kids who live and have no access to this treatment because, first of all, it's extremely expensive and second of all, the government doesn't pay for any of that. So I really know that our movement Save Lives of SMA kids will really change this.

Olya Yarychkivska:

And then second of all, everything... Saving baby Dima has a direct influence on to his own family and his dad being a great civic leader, his name is Vitaliy Svichynsky, who saved Odessa, and essentially during that time, he called up on all other civic leaders to start going into government jobs to take up those government jobs and to start changing Ukraine from within. So that's what he did after the revolution. He started working in the government and essentially trying to make a difference. His core value is, like, zero tolerance of corruption. He's this new kind of leader that Ukraine really needs. And if his son is saved and he can focus again on going back into the government and doing what he does best and he has shown amazing work in the Odessa region. I'm telling everybody who is listening now, mark my words, I really think this guy will be a president of Ukraine one day.

Olya Yarychkivska:

If you're listening to this podcast, I really am urging you to donate to baby Dima, even if it's just the price of your morning coffee or lunch or a snack or anything. You can go on GoFundMe and just type in Save Dmytro, D-M-Y-T-R-O, and you will find the campaign. We have raised over 55% and you will be able in the future to say, "Oh, hey, I helped to save the son of Ukraine's president," so that will be pretty cool.

Andrea Chalupa:

So, I cover a lot of dark topics on the show and one of the things that keeps me hopeful about the future is Ukraine's own history and what Ukrainians are doing to fight for their future and build a better future for themselves and their children, as you all are doing. Just to give our audience some background of what I mean is Ukraine could have been wiped out by Stalin's genocide famine in 1933 and it was a

prison under Soviet oppression for many decades. Then it came out for independence, of course, as communism fell.

Andrea Chalupa:

During that period, of course, it survived Chernobyl. So there's all these horrific things that have happened throughout Ukraine's history but it keeps surviving and thriving and it's getting better as a country. It's getting more open—knock on wood—as a society.

Olya Yarychkivska:

Mmmhmm (affirmative)

Andrea Chalupa:

As we saw in the 2013, 2014, Euromaidan Revolution of Dignity, that was an organic spontaneous uprising, where people took to the streets because they had enough and they no longer wanted to be stuck under Putin's puppet, Viktor Yanukovich and it was people from all walks of life across Ukraine joining together on the square, millions of people filling the square. Even when photographs and videos of police violence and people, protesters being brutalized, went viral, more and more people just came to the square to show their support and solidarity, and they were ultimately successful. There was no intervention from any major global superpower.

Andrea Chalupa:

In fact, European officials tried to broker a peace deal that would have allowed Yanukovich to stay in power and a Ukrainian activist jumped up on the stage and grabbed the microphone and said, "No way. Yanukovich has until 10:00 AM to get out, or we're going to make him get out." and Yanukovich fled that night to Russia, where he's been hiding ever since.

Andrea Chalupa:

What happened is, Russia quickly invaded. It seized Crimea right away. Then it started to invade the East. And because the military was so hobbled from many years of corruption—and Russian-driven corruption of the military, you had ministries of defense that had Russian passports—so what happened was volunteers, protestors, the people that drove the revolution had to then change course and become volunteer soldiers and medics on the front lines of being invaded by one of the most powerful militaries in the world and that's what Dima's father did. And he led the movement to protect Odessa.

Andrea Chalupa:

Odessa was originally in Putin's plans. Putin was like, "I'm going to take back the parts of Ukraine that Catherine the Great conquered. And I'm going to give the Russian people Novorossiia, new Russia." Dima's dad and other activists were like, "No, you're not."

Olya Yarychkivska:

Right.

Andrea Chalupa:

And they stopped him and it's just so incredible. Then, as you said, they went into government. They ran for office themselves. They joined parliament.

Olya Yarychkivska:

Mmmhmm (affirmative)

Andrea Chalupa:

So, you're fighting all these wars that Americans are just now discovering themselves, the disinformation warfare, the propaganda warfare, the asymmetrical warfare, how corruption is weaponized, and of course, you have the much added difficulty of a real hot war on your borders, and being used as a pawn by Russia against the West and the Russian people, too. Throughout all that, Kyiv remains a hotbed for the Russian resistance. There is a lot of Russian Ukrainians and Belarus solidarity too.

Andrea Chalupa:

So I'm very inspired by the work you guys are all doing on the ground I always love highlighting on the show, because that's where my optimism comes from. Anytime I get discouraged by what's happening in the US, I'm always reminded by groups like yours and people like you that are just doing the damn thing and just springing out of bed and saying, "How can I make the world a better place today?" And just to highlight that, I want to tell everyone, you, with everything you're juggling, with everything you have going against you—the big "David and Goliath" story that you and your friends continue to live—you are taking on a fundraising effort to raise enough money for the most expensive treatment in the world. It costs what, like \$2.3 million?

Olya Yarychkivska:

Right, \$2.3 million. It's incredible.

Andrea Chalupa:

You've managed to get half of that?

Olya Yarychkivska:

Even more, 55%, essentially, in only two months. And most of the donations are from Ukraine. It's a truly kind of historic fundraiser, I would say, and only due to the fact that it unites all the activists, who have huge networks. All of the media is talking about this now. We have access to all of the different nonprofits and civic organizations, these are our friends, so we are able to publicize that really widely. So it's quite incredible and our goal is to really finish fundraising in one month to get baby Dima treated around the age of six months old. It will be really incredible.

Andrea Chalupa:

Wow. Obviously, baby Dima's story is not just he's going to get the treatment for your efforts, other people across Ukraine will also receive similar treatment.

Olya Yarychkivska:

Right. So we are working on multiple projects in parallel on how to help all the children. Some children are eligible for this gene therapy treatment, but some children are not anymore, but there are other treatments. They are also expensive, and they also have to be taken during their entire lifetime.

Olya Yarychkivska:

But essentially what we are doing here is because, thanks to this campaign for little Dima, we have raised such a huge media presence for this disease, and we found all of these parents with their children. We said, "Listen, we just have to do more about this. There are all of these kids that are suffering. We just cannot leave them behind." And since I found other children, everyday I have been thinking about how to help them. So one thing we started that advocacy campaign 'Life for SMA Kids' and after two weeks of campaigning online, essentially, and the Ministry of Health of Ukraine is also monitoring Facebook and all the online resources, we also have connections with them, but essentially, they already changed their rhetoric and they are trying to make deals for one of the treatment options, which is huge. We are really waiting and essentially, in this month, we should hear the signing of this new treatment for all Ukrainian children with SMA, which will be incredible.

Olya Yarychkivska:

Then, of course, we are campaigning to have a full fledged SMA state program that will start in 2022. We are also hearing from our friends at the Ministry of Health that our campaigning, essentially, is changing the minds and because it's in the news so much, this is the right time to do it. We're just so excited that we can help all of these kids. Starting from here, we can do even more. Dima's dad, Vitaliy, will get back to his government job. He will do even so much more.

Andrea Chalupa:

Oh, fantastic. Where does he work in the government?

Olya Yarychkivska:

Well, he's still in the Odessa government, but I really think that after this, he can just do anything because after seeing how he runs this campaign, the first call of volunteers that I joined and the caliber of people that you have involved in this campaign, I immediately said—and this was at the very beginning, we only had 10%, okay, so a lot of people were saying, "But this is impossible," you know? But once I joined that call, I said, "That's it, this is done. This will be done, for sure. I guarantee it to you. This caliber of people, they will fundraise. We will do it. We will just do it, for sure."

Olya Yarychkivska:

And I think this is a huge experience managing this huge campaign, 100 volunteers that are doing anything from fundraising online to trying to do some events when there is no lockdown, to doing these special auctions for meeting famous Ukrainians. I mean, you name it, anything is done. And just collecting this huge sum of money and talking to doctors and to governments, he's getting an incredible experience in this section and I think it will be huge what he will do after this.

Andrea Chalupa:

So, given Ukraine's own history, why do you think civic society movements like yours continue to persist in the face of such great challenges?

Olya Yarychkivska:

I think when I was growing up in Ukraine, I actually didn't have such a strong feeling of the civic society. I got very much inspired when I moved to the US for college. I could see how volunteering is prized here, how people do so many projects on the side, even small kids, like in kindergarten and in school, and I thought it was really incredible. But I think really it has been catching up really fast in Ukraine, especially with the generation that was born in independent Ukraine, or like me, I was born at the very end of the

Soviet Union. My birth certificate says I was born in Soviet Union, but I have no idea what is the Soviet Union mentality, because I really grew up, you know, my conscious time was during independent Ukraine. So, I think it's this really new generation that can see the possibilities. I think, of course, Euromaidan and the Revolution of Dignity inspired all of us and showed us the power of the civic grassroots movement, the power of people that you can have, and essentially how you can dictate where you want your country to go and how you see your country. I think this is a huge inspiration and that's why it continues.

Olya Yarychkivska:

All of us, all of the civic leaders, see that there still has to be a lot of work and everybody understood at the end of the revolution that this is not the end. Actually, now starts a time where all of us either have to enter government or form non-profits to keep the government accountable and essentially work in all kinds of different directions to change the country, little by little, project by project. This is what keeps us going, because there are a lot of successful projects, a lot of successful changes that happened, and there is still a lot to do. And we know that we can do it.

Andrea Chalupa:

What advice do you have for civic leaders facing their own massive challenges, like corruption?

Olya Yarychkivska:

I think that you have to have your... Stick to your values and don't give them up. I know that a lot of young people in Ukraine are facing this, and for example I spoke to Dima's father Vitaliy and he told me a lot about his government job and he said, initially, when he entered government right after the revolution, it was really tough to be in government because the salaries were not so big. So then, of course, it's no wonder that then you get these government officials who are taking money on the side, who are corrupt, because how can they really feed the family? But, he had very strong convictions and for a few years they endured somehow. Before that, he had his own tourism business that he gave up. Then there was a reform to raise the payment, the salaries, for government officials, and once he entered and he was like the deputy/head of the Odessa local government, he already had a pretty decent salary. He said that if anybody approached him—and he was approached a lot with offers to take money on the side—he just was very firm in his conviction that, "I am against corruption. I don't take it," and these are just his values.

Olya Yarychkivska:

I think all of the activists just have to stay strong, stick to your values, whatever it is, whatever happens. It can be really tough at times, but if you really stand for something, you have to stand for that. Just always believe that you are doing the right thing. It can be hard, but if you have a team and you have others who think like you, you can really persevere and make a change.

Andrea Chalupa:

Thank you so very much for coming to Gaslit Nation, Olya, this was an incredible interview, and please keep us updated on all the work that you're doing for Ukraine. It's so important.

Olya Yarychkivska:

Thank you so much, Andrea. Thank you so much to everybody who listened and I'm just asking you again, if you can donate your coffee or your lunch money for baby Dima, and you can just search on

GoFundMe, Save Dmytro, D-M-Y-T-R-O. I really strongly believe that the story of Dima will not just cure all of these other kids in Ukraine, but also will allow his dad to do some incredible things in the future, including, hopefully, being a president one day.

Andrea Chalupa:

Definitely one that won't get extorted by the president of the United States. [laughs]

Andrea Chalupa:

Our discussion continues, and you can get access to that by setting up on our Patreon at the Truth-teller level or higher.

Sarah Kendzior:

We want to encourage you to donate to your local food bank, which is experiencing a spike in demand. We also encourage you to donate to giveindia.org to help Indians battling COVID-19.

Andrea Chalupa:

We also encourage you to donate to the International Rescue Committee, a humanitarian relief organization helping refugees from Syria. Donate at rescue.org.

Andrea Chalupa:

And if you want to help critically endangered orangutans, already under pressure from the palm oil industry, donate to The Orangutan Project at theorangutanproject.org.

Andrea Chalupa:

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