

OUR LULLABY

Summary

Ondine (or Undine) is a fair hair nymph living in the rivers and lakes of the North. Admired by artists, portrayed by painters, and praised by composers in their operas. She can be found in various mythologies.

Ondine is an avenger, too. By engaging in a relationship with a mortal man, she loses her divinity. Her beauty passes with time and so does the faithfulness of her lover. The nymph sets a curse on him. He will breathe as long as he is awake, when he falls asleep, his breathing will stop. The pain of the betrayed and rejected woman is the source of a cruel revenge and Ondine's lover dies.

"Ondine's curse" is a common name for a rare genetic disease officially called congenital central hypoventilation syndrome (CCHS). People suffering from CCHS are at risk of death whenever they fall asleep, although they have not done anything wrong to "deserve" it. No one knows why they are doomed to constant vigilance, particularly after dark. Every night they need a machine to breathe for them while they are asleep.

One of twelve hundred persons in the world diagnosed with the disease is Leo - the son of a photographer Magda Hueckel and a film director Tomek Śliwiński. They use art to talk about their son's disease called Ondine's curse. A few years ago, they made a film and in 2021 they released an extraordinary music album with lullabies, entitled *Ondinata. Songs for Ondine*.

Kasia Michalak, the author of the feature "Our Lullaby", visited the family to return to the moments when a double bass player and composer, Sebastian Wypych, had worked on the music for people suffering from Ondine's curse. Like Jan Sebastian Bach whose *Goldberg Variations* were to bring an end to the sleeplessness of count Keyserling, Sebastian Wypych creates special music for persons suffering from apnoea and their families. Or perhaps he even tries to propitiate Ondine?

In his works, the composer incorporates the rhythm of the machines helping the patients breathe every night. It is a haunting sound that one cannot break free from. On the other hand, it is a guarantee that the patient breaths. This very special music serves as a background for stories about rage, sacrifice, and fear. But also about forgiveness and fascination with the Ondine's myth.

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(Sound of intercom, opening of the door to the staircase in a block of flats)

SEBASTIAN

Frankly speaking, this whole meeting was both accidental and not accidental. Eighteen months before the album was released, I met an old friend of mine, from my childhood, in Żoliborz¹. We haven't seen each other for some thirty years. And she says: "Look, I know a guy who is helping a couple on a very interesting, important, and beautiful project to find a cure for Ondine's curse. Could I give him your phone number? He's looking for artists, but he doesn't know anybody in the business..."

MAGDA

And this is how Rafał got Sebastian into it... He had told his friend about the project and she said she knew one nice guy named Sebastian. And Sebastian actually turned out to be a very nice guy. He came to visit us one evening. We sat at the table, like we are now, and started talking. And so, Sebastian stayed in our lives for good.

SEBASTIAN

Magda and Tomek told me about their project, their idea, and most importantly, about Leo. Actually, I knew I was in after the first few words. I knew I wanted to help and I knew I would use all my professional contacts among artists, musicians, and singers – my friends – and convince them to join in.

MAGDA

One evening, as we were sitting here with Sebastian, I noticed his ear "moving" towards Leo's bedroom.

(Breathing of a person going upstairs, becoming heavier and heavier)

SEBASTIAN

The sounds I heard at Magda's and Tomek's place were the sounds that penetrated through me, because... I can remember them from my childhood.

MAGDA

And so it all started...

¹ District of Warsaw

(Heavy breathing, doorbell, opening of the door, calling on children)

KASIA – THE AUTHOR

01'53"

A large kitchen table at which the main figures of this story met eighteen months ago, today looks like a drawing board. A five year old Teo proudly presents his colouring sheets while his elder brother Leo, all focused, browses through his new book. The boys will be going to bed soon. For their parents – Magda and Tomek – this is not a promise of a peaceful and quiet evening. For eleven years now, every night has been the time of vigil accompanied by very special sounds.

(Closing the door)

MAGDA

Yes, today I am tired.

I guess, I have not recovered yet after my and Leo's stay in hospital. Last week we were in a newly opened treatment centre dedicated to people suffering from Ondine's curse.

It has been established in the University Hospital in Gdańsk, in cooperation with Rare Diseases Centre, Developmental Neurosurgery Research Centre, and our Foundation.

And... to be able to fully answer your question why it is so important, I have to go back to the very basic information about Ondine's curse – congenital central hypoventilation syndrome. It is a genetic disease in which a person stops breathing after falling asleep. He or she needs to be connected to a special machine – a respirator or a diaphragm nerve stimulator, and a pulse oximeter. Every time they fall asleep, they need to have their own ICU at home or they will simply die...

The key problem is that it is an extremely rare disease. There are only twelve hundred people affected by the disease in the whole world. In Poland, there are approximately forty diagnosed cases. Doctors, who are great specialists in their disciplines, still know very little about it. One just can't know every rare disease there is. In the beginning of December, a special team was set up to treat our kids. This will help us to learn more about the disease. Another thing is that, if we go into the clinical trials stage – which is my dream – there will be a place where our kids, one day, will be able to take the magical pill – a magical antidote lifting the curse.

There will be no magic to it medical terms, but for me, all this is more like a mythical tale.

(Sounds of the breathing assisting devices)

SEBASTIAN

04'47"

Recording of a respirator.

KASIA

Artists and travellers, Magda Hueckel and Tomek Śliwiński, became parents for the first time in 2010.

MAGDA

And so he was born. His Apgar score was 10. The labour was rather difficult. I was exhausted. At first everything was perfect. He was big, healthy, beautiful, and strong. But after five minutes the midwives got concerned about something. He got subdued, and then he was taken to the ICU. At dawn, I was told that the machine was breathing for him.

(Sounds of medical devices)

I remember the first time I've heard this damned two words: ONDINE'S CURSE. I was standing by the Leo's bed. He was two days old. We were standing there, me and Tomek, and she came ... that woman came ... a doctor ... and she just threw, yes she just threw those words at us "I have just read on the Internet about this disease – Ondine's curse. He will probably just lie like that for the rest of his life". It was something like that. And then she was gone. It was ... like a bomb. Like a bomb. A bomb. It was Nagasaki.

And we left the intensive care unit where Leo was staying, and looked on the Internet. I can remember when I first saw her. Standing in a white dress, with some jug, long hair... And then, I have to admit, then I got into this myth.

(Sounds of the breathing assisting devices)

SEBASTIAN

6'34"

Oxygen concentrator.

KASIA

I read about Ondine, a water nymph who fell in love with a mortal man, in an essay by Joanna Bator², written especially for the "Lift the Curse" Foundation.

The water nymph sacrificed her divinity, because engaging in a relationship with a mortal man meant renouncing eternal youth and beauty. *(Heartbeat, breathing)* She must obey the laws of the mortals, as a wife and mother. She is ready for that, yet she does not foresee the consequences. Her beloved is unfaithful to her, because his love passes as does her divine charm. He promised to love her till his last breath and he failed, and when she discovers his infidelity, she casts a curse on him. He will breathe as long as he is awake, when he falls asleep, his breathing will stop. *(Breathing stops)*

² Prominent Polish writer.

The pain of the betrayed and rejected woman is the source of a cruel revenge and Ondine's lover dies.

(Heartbeat stops)

Ondine's curse, the risk of death during the sleep, accompanies people suffering from the disease whenever they fall asleep, although they have not done anything wrong to "deserve" it. No one knows why they are doomed to constant vigilance, particularly after dark.

MAGDA

I have to say that my first reaction was – I've been told it's typical – it was anger. And... I know you "don't shoot the messenger", but the way it was communicated to us was really not what one would expect. At one point I was told that Leo will not be able to go any further than to a balcony. For me, a traveller, it was really devastating. I think any person who has a true passion can imagine what it means to be deprived of it. And I realised at that point – a respirator – balcony – this will be my only journey from now on. But on the other hand, I started to feel really... there was a moment when... I felt enormous rage. I said: "No, no, no!". You will not be telling me how my life is going to look like. And I felt determination to do it my own way.

Obviously it was a long, very long process, when we, me and Tomek, started to look for options, for alternative solutions, but the ones that would not do any harm to Leo, because you know, the responsibility for a child with a respirator and tracheotomy is simply enormous.

(Breathing assisting devices)

8'54"

KASIA

When a musician and composer, Sebastian Wypych, comes to Leo's parents' apartment, he can hear astounding music.

(Archive recording: Sebastian, Magda, Tomek – Leo's parents during recording of sounds of the medical devices)

SEBASTIAN

We've got it, you see, we've got it.

MAGDA

Beat!

SEBASTIAN

There is melody for it...

SEBASTIAN

When I met again with Magda and Tomek, when Leo was asleep, I was recording the device, I was recording Leo's breathing, hooked up to the device, and all other machines, and I turned them into a piece of music, they served as a rhythmic base, as a groove.

These sounds are really scary, but at the same time these very specific sounds of a device in combination with breathing are a guarantee that the child breaths, is alive. So, we have those terrifying sounds which are like sounds from the ICU, intensive care unit, colliding with the sound of breathing, which gives peace to the parents. That they can go to sleep because they hear the sounds. They mean the device is working, the child is breathing.

(Archive recording: child imitating the sound of pulse oximeter)

10"12"

MAGDA

Our first night at home, with Leo?

It was over four months after his birth. And as far as I know, it was the shortest stay of a child with Ondine's curse in an ICU in Poland..., so it was very fast for us to get him out of there. I wanted, we wanted it very much, because the hospital reality is very limited. A child just lies there, sees the ceiling with some ventilation grates. Sometimes you can take your child in your arms and walk around a small room. This is a complete isolation from stimuli. But we had a plan that, although the child is ill, needs a respirator, he will be stimulated.

He will lie on the grass, go for walks, and there is the respirator - we bought an external battery instantly, to extend the operating life of the device. And the truth is that when Leo was five months old, I took him with me for a weekend trip to the seaside, the first time away from Warsaw. It was really, really, fast.

Now we travel with Leo. We do, but it is an enormous effort every time. The logistics is very complicated. And there's a lot of stress, too. But when I see Leo in some really crazy place, I know it is worth it.

He knows the world! He sleeps with me in the woods, in a hammock, right? With all his stuff. He sails with me, he goes hiking in the mountains (*archive recording - Leo's snoring*), so he lives his life to the fullest, but has his limitations.

(snoring, beginning of "A Lullaby for Ondine")

KASIA

Magda Hueckel and Tomek Śliwiński presented the first months of their life with little Leo, in a documentary *Our Curse*.

A thirty-minute documentary recorded with an ordinary camera made an unexpected success and even got an Oscar nomination. The film was a driver of international interest in rare,

possibly fatal, disease. A foundation was established in the USA, with the purpose to centralise the financing of the research on a cure for Ondine's curse.

(snoring joined by beat (rhythm section))

Leo's parents realised that through art they can not only tell their story, but really make a difference and help persons suffering from Ondine's curse.

SEBASTIAN

It is a combination of a machine assisting in breathing and of the oxygen concentrator – and, actually, several other devices. I have photographs where I am recording all those devices. It looks like a technology park. We had many devices, many sounds, many wires and cables. Some of them were machines Magda and Tomek had already forgotten about, some older ones, which they no longer used. I recorded the devices. Then I went to the studio and started to make the rhythm of them.

(Piano added, scat singing)

TEO *(bantering)*

No, no, no...!

KASIA

Look, tell me what's gonna happen next week?

LEO

Next Thursday?

MAGDA

You can count Leo, today it's the ninth...

LEO

My birthday.

It's been a long time since we had a party for classmates. We are going to throw a party, but we are not sure where yet.

MAGDA

Well guys, let's go brush your teeth, ok? It's ten past ten already! It's really late. It's gonna be hell in the morning, again.

LEO

It was hell today.

MAGDA

No, today it was only tiny little hell.

KASIA

15'22"

What time do you need to be at school?

LEO

Eight thirty.

TOMEK (dad)

Kids, go brush your teeth.

MAGDA

Can my monsters go and brush their teeth? Both of them?

LEO

You heard dad. Go, go, go...

MAGDA

Leo, when he goes to bed, to sleep, he hooks himself up to the diaphragm nerve stimulator. We have managed to get the surgery in Sweden some six years ago. This is an alternative method of mechanical ventilation. It allowed us to close tracheotomy. But the stimulator does not operate automatically. It is a box with an antenna, and the antenna needs to be put on the receivers implanted under the Leo's skin, fixed in place. Then we need to switch the whole thing on and it initiates contractions of the diaphragm causing physiological inhale and exhale.

And Leo needs a pulse oximeter on, too. He can do it all by himself, but... we are not ready and it's too much responsibility for an eleven-year-old boy, so he hooks up to the stimulator, but we check everything, switch on the pulse oximeter, and then we leave him. He either reads for a while or simply goes to sleep.

And usually the first phase of the sleep is rather peaceful. But later, around midnight, when we are getting ready to sleep ourselves, the alarms begin to go off. They are triggered by various factors. The antenna may get dislocated and one of the receivers is not working properly. Or Leo may be lying on one side and his breathing may become irregular. There may be some discharge in the respiratory duct and he doesn't feel he needs to expectorate, like a healthy person who feels they are suffocating. Because of the disease, Leo doesn't feel discomfort caused by shortage of oxygen. If he dived to follow Ondine, a siren, he would follow her ... to the end. The body does not react to accumulation of carbon dioxide and shortage of oxygen.

17'15"

So, whenever something is not right and the saturation drops, pulse oximeter informs us. We get up and check what is wrong. You have to be wide awake instantly and think clearly, to be able to find the reason of low saturation. And act. Then we go back to sleep until another alarm wakes us up.

And it's been like that for eleven years.

He will never be able to stay long at a party. He cannot stay overnight at a friend's house, as other kids do, because no one is ready to take care of him at night. He already misses out on a lot of things. When there is a school camp, he spends all day with the kids, but then he goes to sleep with dad in a rented room. And, obviously, we have to find the time to go to the camp with him. So far, so good. But in a few years, it's the nights that will be the most important at the camps, not the days... (*beginning of "A Lullaby for Ondine"*). So, our biggest dream is that

he will be able to live normal life. That he doesn't have to worry about his life. That we don't have to worry about his life every single night.

A Lullaby for Ondine performed by Anna Karwan

*I know a lot of night songs
Sweet lullabies, so quiet
But this one is a loud one
But this one we keep private...*

*Though it may seem so roaring
Like an electric organ
This song lets Dad or Mummy
Sleep for a peaceful moment*

SEBASTIAN

And then I thought we need some beautiful lyrics for this song, talking about it. So I got in touch with Jacek Cygan³. I told him the whole story. And he, without hearing the machines, sent me the lyrics two days later. And then I began to put it all together in my head... creating the melody to match those machine sounds. And this is how *A Lullaby for Ondine* was made (*double bass begins playing*).

All sounds in *A Lullaby for Ondine* and my pieces included in this double album are played on the double bass, because this instrument is my companion, and we travel together through the world of music. I have always dreamed I could present the double bass from a new perspective – not as an instrument you see on stage, but you actually cannot differentiate the sound, but as an autonomous source of all sounds – of harmony, melody, and rhythm.

MAGDA

20'05"

As many mums, I used to sing Leo to sleep.

And this lullaby thing has always been there with us... quite soon this idea germinated in my mind that maybe... since this whole disease is connected with sleeping, maybe we should think about lullabies.

Another thing is that the process of falling asleep is accompanied by very weird sounds. It is an orchestra accompanying people suffering from the diseases. And we thought we needed to somehow change the bad connotations. So that falling asleep would not be associated by our kids and parents of other kids only with those sounds, but also with something nice. We wanted to rearrange it somehow, change it, to make this falling asleep a better experience.

And these mythical thoughts came to my mind. I am interested in spirituality of various cultures. I travelled a lot in Asia and Africa. I have watched people making "deals" with their gods. They bring them gifts, make offerings, burn incense, sing.... All cultures have it. And so, after my first reaction was hatred for Ondine, rage at her at how she could cast this curse at my child, then, at one point, I looked at her from a completely different perspective. I saw a hurt woman

³ One of the Poland's best known lyricists.

betrayed by her beloved, who just got very angry.... and I felt – that’s incredible – I felt empathy for this mythical goddess.

And... I have thought to myself – maybe this would help, if we just sing for her. To mollify her, to make her simply... lift the curse.

I know that only a medicine can lift the curse... I’m a rational person. But on the other hand, on some energetic level, I feel that it simply needs to be done... (*music*). One needs to be optimistic. We need to... we need to do good things and try not to... – not to multiply the negative energy. What better way than to do something good and give people a tale which, all in all, is a beautiful tale. Somehow, it is also about forgiveness. Every one of us has been hurt at some point by someone... It’s no use getting upset. We need to break this spell.

(*double bass*)

SEBASTIAN

I could say that music is like the air.

As we breathe air, our souls breathe art; music is the air for the soul.

Those rhythms and sounds come back to me very often. They are in my head and in me. The whole project is a kind of journey for me, a return to my childhood and to my early adult years, too; to the sounds of my dad’s oxygen concentrator.

My dad died of asthma. He suffocated.

He was lucky enough to live until he was 70. But the last twenty years he was hooked up to the machine, because of very limited lung capacity. The machine was with us practically all the time. As a grown-up man I used to lug this heavy machine, weighing some 40 kilos. When we were going away somewhere, we had to make sure there would be power supply, so we could switch it on in the car, if necessary. So, all this somehow make up one whole.

We have a chance to find a cure for a disease which seems incurable and at the same time face the memory of another incurable disease, I mean asthma, in advanced stage, that my father was suffering from.

It is a meeting of myself as a child and myself here and now, as an adult. That made me feel I had to do it, there was no other option for me.

(*music dies out*)

MAGDA

It was an enormous effort to release this album.

24’21”

When it was finally done, I realised it had been six years since my first e-mail concerning it, sent to someone. For four and a half years I had been going from one person to another. Someone had promised something and then they were gone. Ten meetings with someone else, it looked like we were making some progress. And then those people just disappeared. And so on, and so on. So, it had been a really long way. And eventually, our friend – Michał Diling – helped us to get some financing for the project. Some other people joined in – wonderful Rafał Wielgosz who became the driving force, the guy managing and organising it all. And through Rafał, we got in touch with Sebastian. But he hadn’t even known Sebastian himself. He told his friend about the project, and the friend knew Sebastian. And Sebastian really got into it. He is

a great musician, a great artist, very versatile. But he is also a man with big heart and enormous imagination.

Thanks to Sebastian, we have managed to attract really top artists, like maestro Maksymiuk, Gaba Kulka, Kayah, Ania Karwan, or Ralph Kamiński⁴.... And many other artists, even folk ones. We wanted folk artists very much, because the whole story is connected with a legend. It is phenomenal to meet all these people(*applause*) who simply want to help us.

TOMEK (*Leo's dad*)

And now Magda will say a few words.

ANNOUNCER

Magda!

TOMEK

Magda Hueckel, who has set up and managed the Polish CCHS Foundation with me. Our foundation released this album.

(*applause*)

MAGDA

For ten years, every night we...

KASIA

In February 2021, the first and so far the only concert of the *Songs for Ondine* took place.

MAGDA (*continuing*)

It is hard, but we can see the hope. The scientists have learned the mechanism of the disease. We need money to ensure funding of the research, to ensure financial liquidity until 2028 so they can continue the research and get market authorisation for the cure (*Lullaby for Ondine*). And this is why we made *Ondinata* – a double album with these beautiful songs with which we want to bring some peace and harmony into the lives of CCHS patients. I am here today to ask you a favour, to ask for your support in our efforts, because we won't be able to make it on our own. And we want to give our son, for his eighteenth birthday, freedom. We want him to breathe.

And not only him, but all kids with CCHS:

Julek,
Ania,
Emilka,
Kuba,
Oliwia,
Sara...

⁴ Naming other prominent artists

*This lullaby sounds so bizzare now
It praises din and clatter only
So good to bring us peace at night-time
This lullaby is sung to Ondine*

LEO

Can you hook me up on the oximeter, mum?

MAGDA

I'm coming.

(Connecting Leo to the device)

You're tired, aren't you?

MAGDA

For us, it was important how the album ends.
It ends with the piece based on the rhythm made by the respirator and the pulse oximeter.

SEBASTIAN

The sounds of the devices stop, but breathing continues. It means ... we can make it! There will be a happy ending. There will be a cure and we will lift the curse of Ondine, say goodbye to the machines. And all those suffering from the disease will be able to live normal lives.

MAGDA

This is how the album ends. And I do believe this is our future.

And then we will finally have a good long sleep *(smiling)*.

(Breathing)