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Status Epilepticus

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An intense, even frenetic activity of the brain and still, we don't know about her thoughts.
We don't know about her emotions.
We don't know about her sensations.
What we can see is a real graphic representation of that cerebral activity, and it should stand for the scientific criteria of life.

If brain activity leads to heart activity, diaphragm activity, and the blinking of her eyes, or if brain activity simply doesn't interfere with the others, we also don't know.

Better not to talk about consciousness!

Life, whatever it means, just flows. Whirling river down the hills ...

The diagnosis was antenatal: an indefinite cerebral cortex defect in the ultrasound. But it was late in pregnancy. And the parents didn't really understand what it meant.

"Prognosis is uncertain." "Central nervous system is very plastic." Those phrases didn't help in making a choice, if there was still a choice.

If ever there is a choice ...

In the pediatric intensive care unit days and nights are all the same continuity of cold experiences.

Do the machines and all technological apparatus need to be prioritized?

Is temperature as cold as people's perceptions?
Even intense activity cannot warm cold air inside—intense
activity of her shivering body.
There is also an intense activity of other bodies that come
and go.
Severe sick children come, replacing those who leave well.
Some children go, despite the up and down movements of
hands, in cardiopulmonary reanimation.

Staff come and go.
There is a noisy balance of nurses changing shifts.
There is also a strange symphony of alarm sounds in the
surrounding ambience. Does she hear it?
Is she annoyed by it all?
Is she afraid?
Maybe she is afraid of touch—gloved touch. Properly, she is
afraid of tracheal aspirations. She is afraid of venipuncture,
arterial puncture.
It is more than fear.
Agony is something that is felt deep inside.
It cannot be explained, only felt: a penetrating, pungent pain
into immobility. Does she feel pain?
Is she in agony?

Now, as anti-epileptic drugs sedate her, the eyes keep closed.
Light has gone.
Communication is also gone, or at least, the impressions of
them.
No movement.
No reaction. No smile ...
No social interaction.
Dedicated parents that are not recognized by her, eventually
go down. Blue, like the colour of those closed eyes.
Blue like the waters of the whirling river.
Blue like the tears that are kept hidden.
Sadness, restlessness, misery!

Her parents have learned that brain defect is life defect. It is
their misery.
They live no life outside hospital. They live no perfect life
there inside.
They trust nobody else. It seems they lost faith.

But then paroxysms stopped.
No more fever.
No infection.
No change in ventilator parameters. No transfusion.
No hope.
Only the clock on the wall continues with its circular pulse.
Seconds, minutes become a whole year.
A cake, a gift, balloons ...
Some secret words whispered in her ear.
Maybe some words can now comfort them.
Maybe those words can now free her.
Maybe some words ...

Activity,
agony,
misery,
even liberty—
they are only words now.

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