REFLECTIONS: NEUROLOGY AND THE HUMANITIES

Section Editor Michael H. Brooke, MD

Reflections for November

Vesper Fe Marie Llaneza Ramos, MD

Address correspondence and reprint requests to Dr. Vesper Fe Marie Llaneza Ramos, University of Nebraska Medical Center–Creighton University Medical Center, Omaha, NE vesper.ramos@yahoo.com

LOVE IN THE TIME OF HUNTINGTON'S DISEASE

I am a mother.
I used to be a wife.
I am not sure if my son
Remembers still.
Maybe that is better.

I have one child. My son is thirty-four. He lives with me. He has no wife. He decided long ago Not to have children.

Huntington's.
Used to be just a town in Long Island
Or a beach in California.
When his father
Was first diagnosed,
My son and I were both afraid
For ourselves.

How do we survive?
But we made do.
Then the genetic tests,
Those so-called
Blueprints of life,
Ha!
The blueprints said

My son would have The disease too.

My son and I were both afraid. Afraid.

In the name of the father And of the son.

We see the small jerks, The subtle funny motions, That probably went

Unnoticed with my husband. And my son would look up to me

With the same stare

He used when he was three,

About things he did not understand.

I raised a brave son. A soldier

Who held his father's hand Through bedbound pneumonia

And even jokingly said

"Do not be afraid, I will soon follow."

But I know he is afraid. He cried when he kept on falling. Impulsive. As the therapist described him.

It could not be farther. My son has always Always planned his life.

Living Will is done.
For a man—
A good man
Who told me,
"Mama, if I should
Kill myself,
Know that I put up
A hell of a fight,
For I know the grief
That it will bring to you."

It will not be him Who kills himself. It will not be him.

His doctor Sees him once a year. There is nothing They can do.

I see him every day, And more and more, I see less and less.

What plague is this?

What protein? A protein?! In the name of the father And of the son, My God, my God ... I accepted widowhood. I am a mother.

Do not let me be in vain.

For as long as I can.

But then my boy's
Words come back to me,
"Mama, when the time comes,
I will tell God to take care of you."
He will take care of me.
Let me now hold
His writhing hand



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