

Unveiling the Dragon

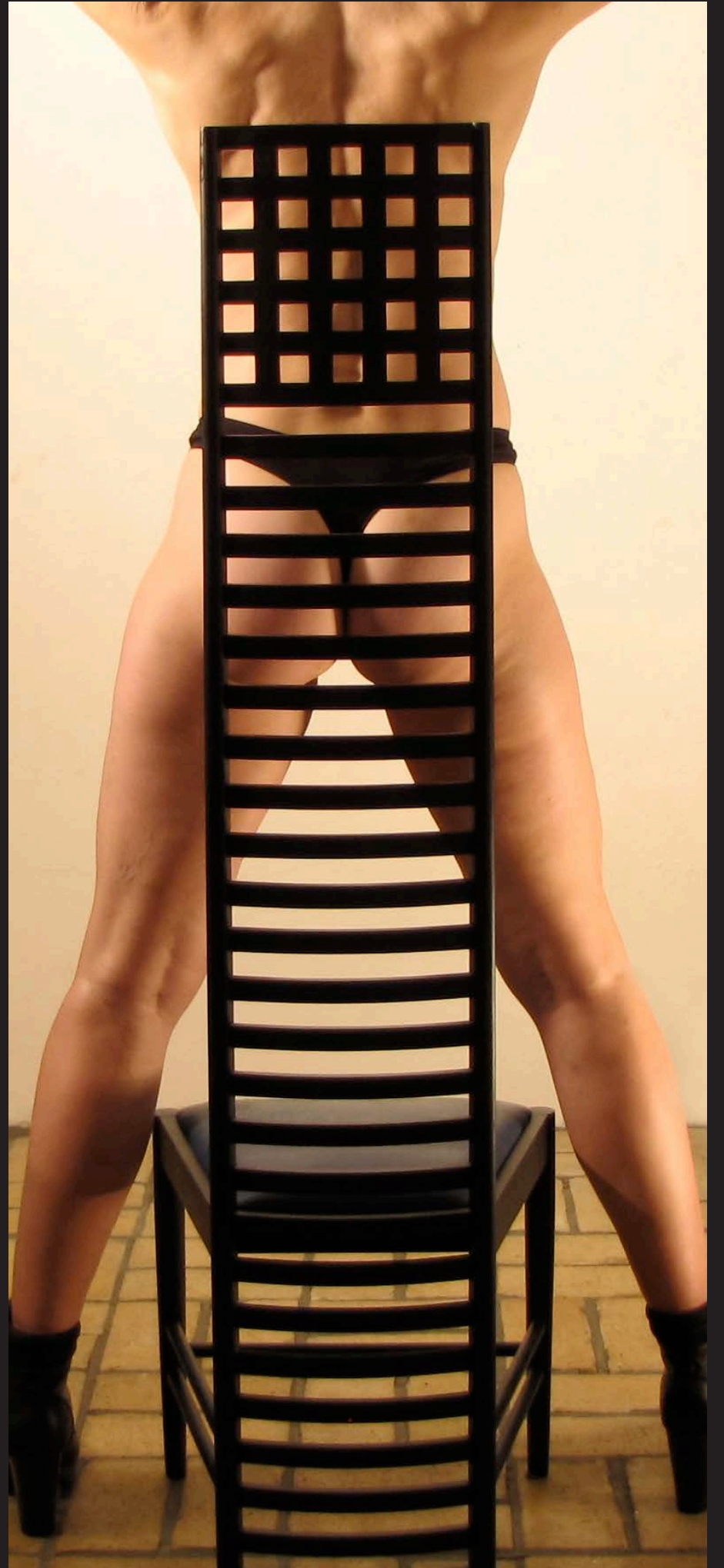
Parkinson's Disease Exposed



Just an old lady with Parkinson's

*“It is not what you look at that matters,
it is what you see.”*

– Henry David Thoreau



Enter the Dragon

I stand before you naked and alone.
Parkinson's took my career, my financial
independence, my self-confidence, my
youth and my sex appeal. Sometimes I
can see only the monster in the mirror.

Things are not always as they appear.
Mostly you see what I allow you to see.

I choose the exposure.
This series of self-portraits depicts my
“still life.”



Looking at Parkinson's Disease, age, femininity and strength

I am 49 years old.

Diagnosed with Parkinson's disease for 12 years. Working half time, waiting for brain surgery to relieve my symptoms.

An estimated seven to ten million people are living with Parkinson's Disease.



KNIGHT BY DAY

*The children play
Games on the computer
Their robust glee growing louder
While I silently fight
A real dragon each day.*

*Successes were many and
Quickly my status raised to Knighthood
Destined to wander alone
In darkness, pursued by – yet
Evading – my dragon.*

*The Knight that I have become
Grows weary
And stiff,
The chainmail is
Heavier each day
Turning my steady strides
Into the shuffling steps of the old.*

*This armor
Once used as protection
Masking my face
Torso and limbs
Entwining my body*

*Now holding me captive
With each step,
Each breath,
Each thought,
Each day...*

GH 01-06-11

*Parkinson's disease (PD) is a chronic and
progressive movement disorder, meaning that
symptoms continue and worsen over time.*

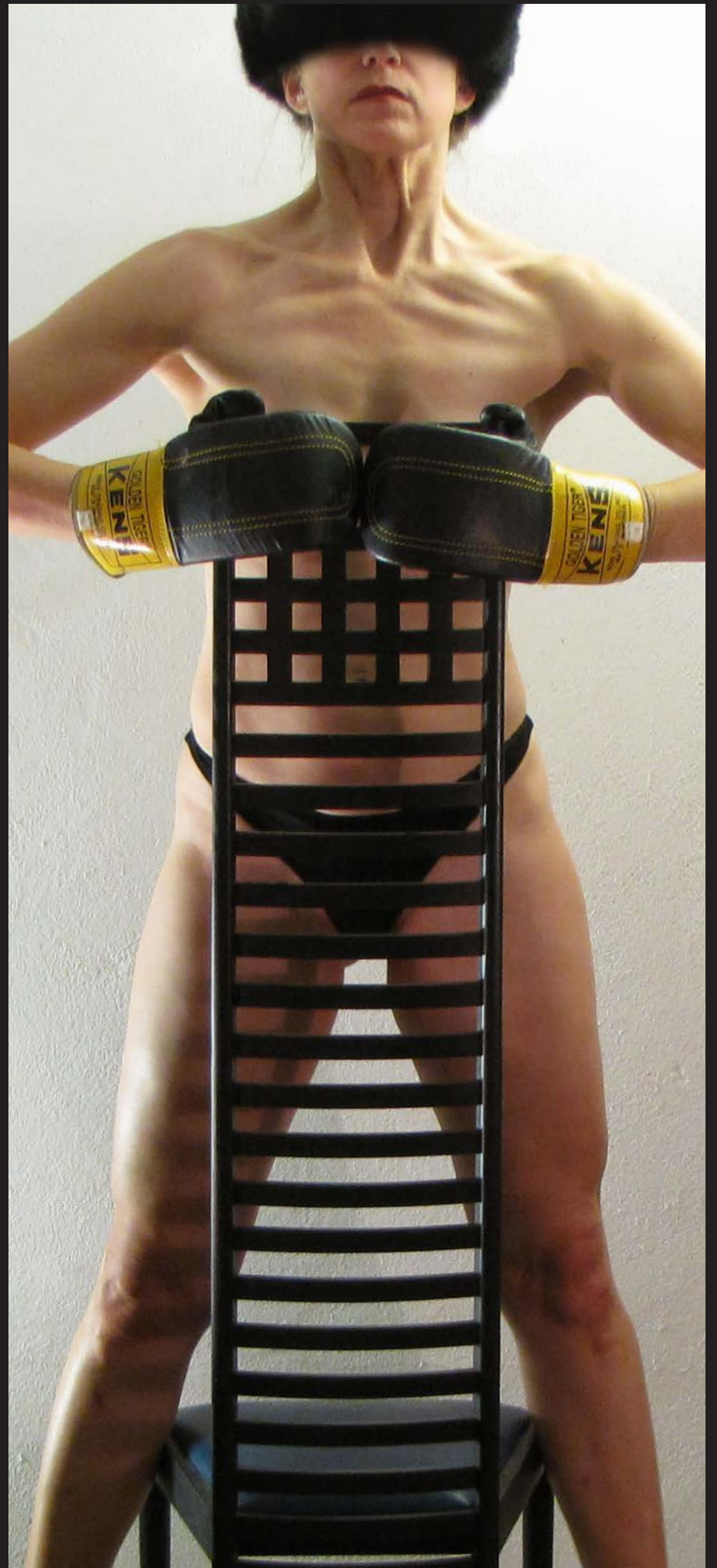
Fighting back

I have no choice but to fight back.
What else shall I do? Lie down and let
the tide roll over me?

This is my dragon.
What is yours?

Survival depends on developing skills
like acceptance, and letting go, finding
balance with control.

*Research has shown that those who take an
active role in their care see an improvement in
their Parkinson's symptoms.*



Finding balance – both physical and mental

Control. I'm trying to regain control of my body, my mind, my future, while simultaneously striving to accept the unacceptable reality of my limitations. Opposite ends of the spectrum pulling at me in opposite directions.



In my shoes

I am six feet tall and always loved wearing high heels.

Consider how much energy it takes when you feel you are walking on a tightrope all day? The tension in your shoulders, back and legs being almost unbearable.

One misstep and you will
“DON’T FALL!”



Judgement Day

I have been accused of being drunk when I am “off” and accused of having faked symptoms when I am “on.”

Some cast judgment on the homeless, the poor, even the chronically ill.

We must not listen to them. They bring us from Invincible to Vulnerable.

People with disabilities regularly identify societal attitudes as the most potent and negative stressor in their lives.



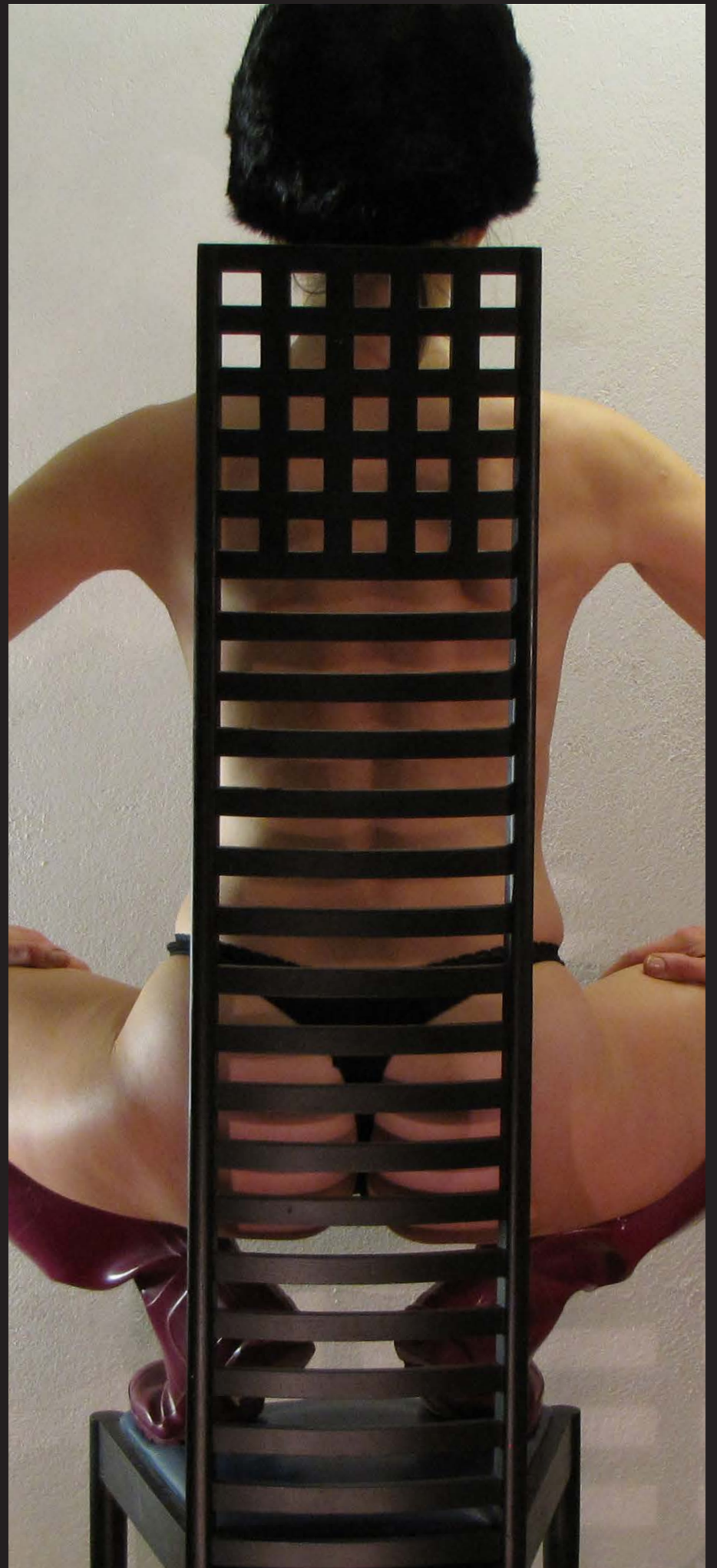
On my terms

Exposing myself – both mentally and physically – is a means of regaining control.

Allowing myself to be vulnerable in reality only makes me stronger.

This paradox raises awareness of Parkinson's Disease, while challenging how quickly we judge one another.

An estimated 4 percent of people are diagnosed with Parkinson's before the age of 50. Men are 1.5 times more likely to have Parkinson's than women.



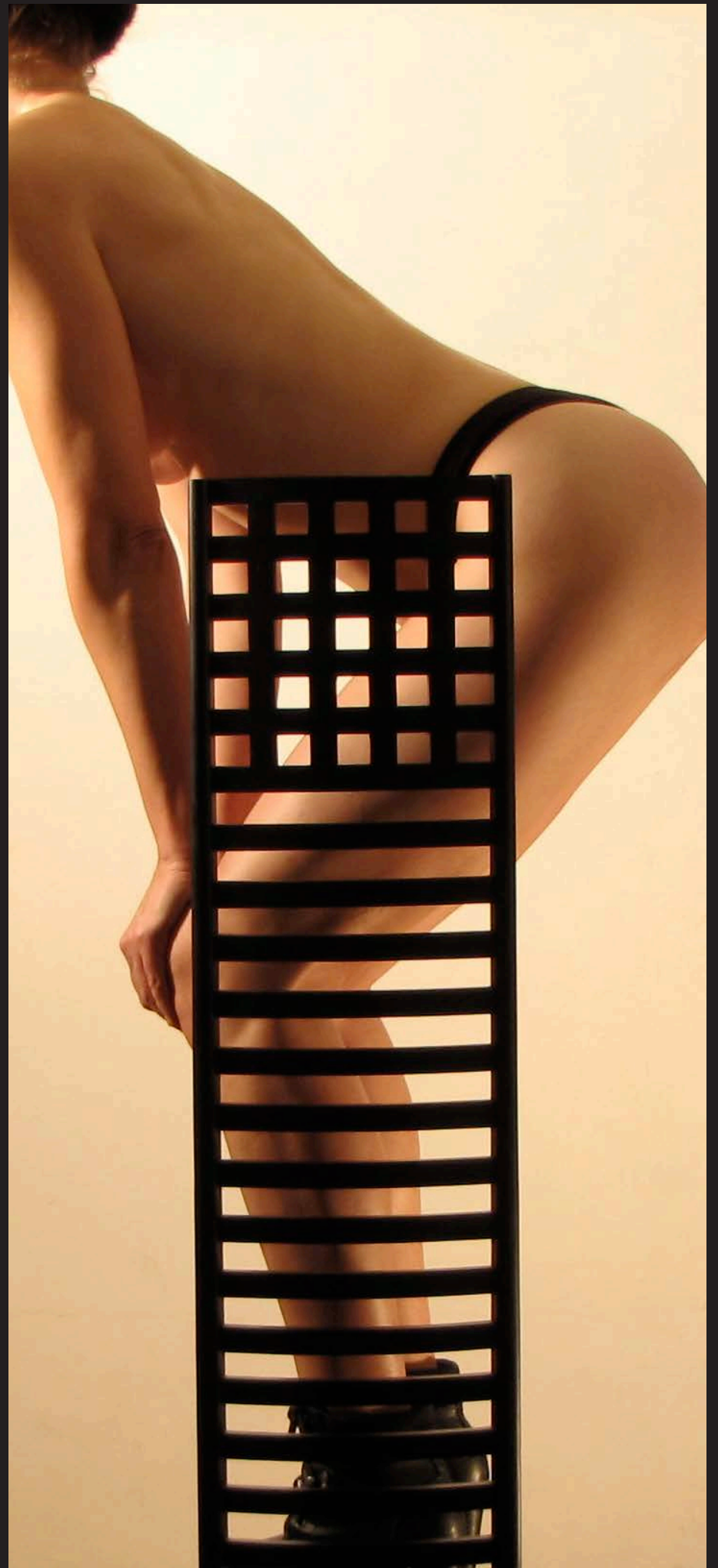
49 and holding...

I'm lucky. I have good genes and I have always liked sports. When I grew up I thought mid-life was age 30, and thereafter one would never fit into a bikini again.

I was a kickbox and yoga instructor in addition to my professional career. Before Parkinson's, I was lucky to be in shape, to be aware of my body.

Intensive exercise can help people with PD walk and move more normally.

Dr. Petzinger

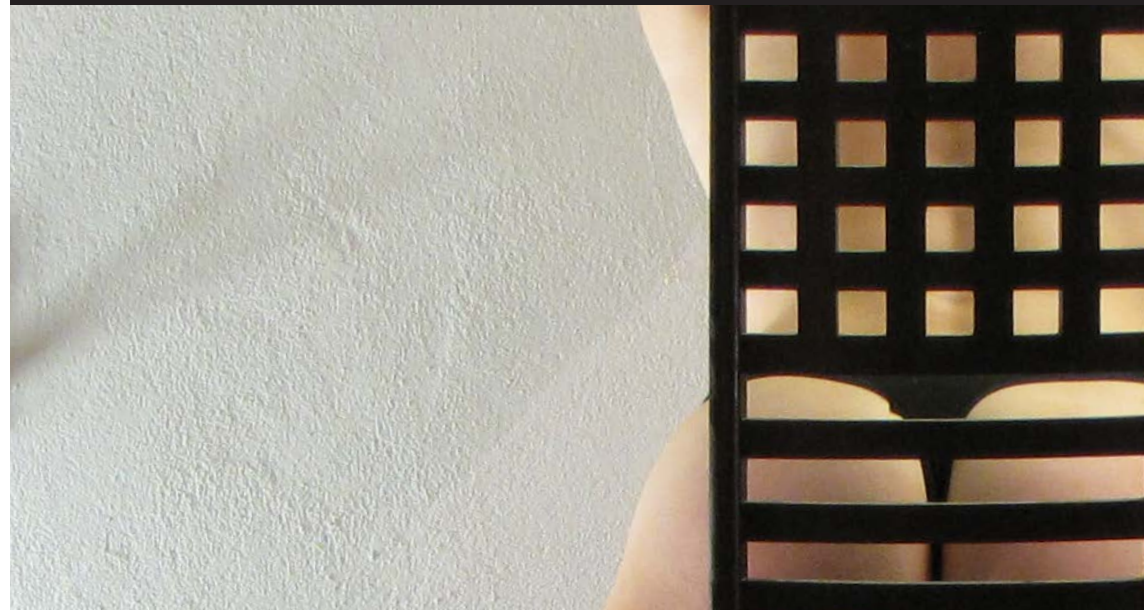


What is sexy?

Having the confidence that you can walk into a restaurant without stumbling. To be in control of your motor functions.

Willing your hand and arm to stop shaking so you can hug your partner.

I watch like an outsider as my body shakes and cramps – things I cannot control.



Strength is reality

Above all this sickness is life itself.
Real life.

Two years ago I didn't think I could
look like this. My results from intensive
training: regained strength, muscle
tone, and confidence.

I depict what a real woman
looks like. No retouched photos.
Truth is the only reality.



New Perception of Dragon Tales

*You and I
Our fate was sealed,
Perhaps at birth –
We may never know
When or why.*

*The chosen few
Sounds noble
But with no choice
Specialized Dragon slayers
We became.*

*Species vary,
Thus battle tactics vary,
But still dragons
By whatever name
They are called.*

*This fate we share
Almost becomes
An occupation,
Almost consuming us
And we begin to converse in
“Industry standards.”*

*This being just one aspect
Of life
Like Superman and
Wonder Woman
We look for phone booths
And private places to twirl
Temporarily transforming us
Into normal, office workers.*

*Unlike our superhero role models
Regular humans can see our duality
And the effects of Kryptonite.*

*Some view us as strong
Others see weakness
Still others disbelieve.*

*But without many words
You and I sense the complexity
Of the other's life
Understanding
How exhausting this duality can become.*

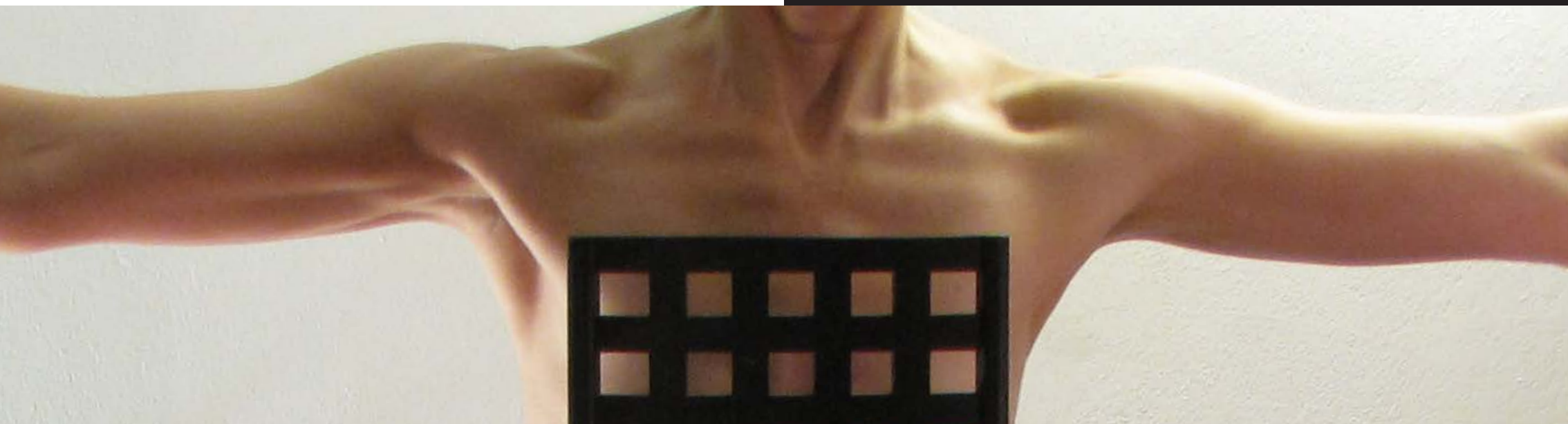
*Dragons, each unique and responding differently
To the individual slayer.
Thus we forge on,
Honing skills, seeking other slayers,
Comparing battle tactics.*

*Listening and learning
From those who have gone before us,
Those who can
Shed a small light in darkness.*

*Slayers are strong
Or they don't survive.*

*Friendship grows as we walk on
As days and years pass by,
Different
But still we both must thrive.*

Deep brain stimulation



I used to call it a lobotomy, but that was before. Now when the 26 pills a day are not working so well, a brain operation doesn't sound so bad.

Medication costs for an individual person with PD an average \$2,500 a year, and therapeutic surgery can cost up to \$100,000 per patient.

Electrodes will be placed in my head by drilling through the skull. A wire will be implanted, running just under the skin, around my ear and into a pacemaker device that will sit above my left breast.

Sounds a bit grim – but hey, we have options.

4 a.m.
15 November

*I wake
I shake*

*Then blink
And think*

GH 2013

Total exposure

It is 4:45 a.m. My name is Grace. I woke up this morning because my neck and shoulder muscles are stiff and cramping, because I need Dopamine. This is what it is like to be “off,” how I am without medicine.

It took me five times to type the four-digit code to open my telephone. Every morning I stretch, but pulling my shoulders up is challenging. So is placing my hands on my shoulders, rotating my elbows into large circles.

I cannot control my hands. Walking is difficult. Throughout the day I swing from “on” to “off.” Medicine, diet, stress, sleep and exercise all affect the swings.



Some people wait until they are dead to give their bodies to science

I decided to do it now by sharing my
story and photos, to challenge
stereotypes of the chronically ill.

*People volunteering to participate in clinical
trials is not keeping up with the growth of
available trials. To find out about clinical
trials and how to participate, please visit
www.PDtrials.org*

