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## The Child Eclipsed

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### On the Light Side

*We named him Raistlin after Dragonlance's beleaguered but brilliant dark wizard—a testament, perhaps, to intellect, our most cherished attribute, the quality we most hoped he possessed. Unprepared parents-to-be that September sixteen years ago, my boyfriend and I were recent college dropouts—youthfully selfish, transiently poor, recklessly apart from family—so ill-equipped for the adulthood that a harrowing labor and a baby's visceral cry would thrust upon us. However full my present—my three young children teeming about loudly with life, light, and laughter; the errands and worries packed end-to-end—he remains with me always, as he was that early morning, wrapped in my unsteady young arms. My tiny Raistlin, far too small for his imposing name—bright eyes, outstretched fingers, rosebud lips—breathing his warmly oblivious, perfect baby breath as I think, This is impossible, but glow with unspoken hope.*

*Near his neonate's crib, a brand new teddy bear  
watches him earnestly.*

## Part I: Full Moon

### *Echoes*

I appealed longingly, wistfully, to those romanticized memories of recklessness, gleeful irresponsibility. It was February 1997. I was thinking of Chicago, of the hitching mechanical noise the turnstile made when my illegitimate rider's fare—a stolen metal washer the antiquated system recognized as a token—allowed me passage on the L. The satisfying crunch my knee-high boots made when they punctured the snow as I sprinted down Belmont and Broadway in my too-short shorts, always running from something. Compunctions, self-consciousness, guilt, age—they never caught me back then; I'd successfully holed up in that unfurnished studio, smoking, drinking, and stealing them away, brandishing my questionable jobs, questionable friends, the questionable relationship that had landed me there in the first place—wards against these things, these unforgiveable, unforgiving heralds of adulthood.

I'd left Chicago a month earlier and moved to central Illinois—to get away from all that, I told everyone—but in the rare moments I actually spoke truth, I would admit I only left to follow *him* again. I should have stayed there, I now thought—I should have kept running. Because when I'd paused for a moment, adulthood had in-

sidiously ensnared me—trapped me with this tiny manacle now sprouting inside me. And I *resented* this fetal fetter for divesting me of my beloved freedom—until the morning I gazed into eyes so like my own that I offered myself to the bindings.

### *Origins*

Their beginnings are deceptively auspicious, these rarest of fetuses comprising only one in 100,000 live births worldwide.<sup>1</sup> They bud and blossom like the others, tiny fetal brain cells already proliferating between gestational weeks 15 and 20.<sup>2</sup> Scientists who mine these burgeoning new moons, mapping cranial surface deformations, analyzing budding shapes, will observe in second trimester brains full-scale growth patterns and rapid frontal and temporal lobe development.<sup>3</sup>

At birth, these infants appear physically and developmentally normal, possessing standard sucking, swallowing, crying, and mobility reflexes.<sup>4</sup> Seemingly typical hand-sucking, diaper-clad babies, they blink gummy-eyed into the new world's intrinsic promise.<sup>5</sup> Their heads predictably intact, their brain stems fueling robust baby vitals, they embody all that is a newborn's innate potential.

## **Part II: Half Moon**

### *Echoes*

Born four weeks premature, our new baby boy nonetheless passed every standard vitals test. “He

is our grandson,” my boyfriend’s father declared in fervent, halting English. “You cannot give him to strangers to raise.” He turned coolly to me, the girl he had pegged for the last two years as “bad news” due to my prior college smoking, failure to speak Chinese, and inability to use chopsticks or cook duck—despite my Asian features—and croaked, “We will help you.” The prospect of parenthood no longer an impossibility, we sent the social worker away and abandoned our plans to put our baby up for adoption.

We completed the necessary paperwork, requested his birth certificate and social security card. It was almost time to take our baby home. The doctor just wanted to run one more test—a previously unscheduled MRI—“just to be sure.” We exchanged furtive glances, silently congratulating each other on being such grownups.

And then my hospital door opened. Obscuring its entrance, his expression a spectral pall that smothered our neophyte pride, the doctor said, “I need to talk to you.”

### *Origins*

Sometime during the second trimester, a triggering event, sometimes environmental, not only halts but *reverses* certain fetuses’ cerebral development. While two opposing theories—*dysontogenesis*, or early organ development disruption,<sup>6</sup> versus *destruction*, cellular brain necrosis<sup>7</sup>—seek to explain this mechanism, scientists overall favor the latter, proposing that a distinct clotting event suffocates and subsequently lays waste to deprived brain tissue.<sup>8</sup>

What causes this initiating vascular event? While scientists implicate factors ranging from fetal brain injury to maternal interuterine infection or exposure to environmental toxins, they can neither agree upon nor identify one single, definitive cause.

A few days to several weeks following birth, the veil concealing these infants' underlying pathology—a rare, congenital condition called *hydranencephaly*—begins to recede. Previously content newborns may suffer seizures, involuntary jerking, and respiratory complications<sup>9</sup> and exhibit discernible new physical symptoms, including upper facial and skull deformations, increased muscle tone, and escalating irritability.<sup>10</sup> At this point, they may also present with associated congenital conditions, joint curvature, kidney absence, poly-valvular heart defect, and trisomy.<sup>11</sup> And at once, the waxing, burnished jewel that is new parents' highest hopes begins to wane.

### Part III: Crescent Moon

#### *Echoes*

Sometimes I think it must have happened to someone else, someone else's child, because I can barely remember receiving the diagnosis. I perceived both of us jerkily nodding in unison as the overhead lights hummed impassively and the walls became so unbearably white that I had to flee that airless, sterile room. I had to flee from my body, from this pronouncement—but there was nowhere to go.

Though the white seared my eyesockets, I willed them bone dry—don't cry, don't cry, I told them.

My boyfriend's mother wrung her hands dramatically. It was our fault, she reasoned—we'd arrogantly tempted fate by giving him that brilliant dark wizard's name. She keened, "My poor baby, my poor baby," until my boyfriend's sibilant, "He's *our* baby," silenced her. And just like that, the grandparents, along with their offered support and admonitions against strangers raising their grandchild, disappeared.

Repurposed, the social worker reappeared clutching a stack of papers, brochures, "options." She and her cohorts stood straightbacked, peppering the "you-don't-have-the-resources-to-care-for-him-properly" decree with words such as "indigent," "the state," "specialized needs," and "supplemental social security income."

We transferred our baby to a recommended state-funded special medical care center. The nurses there assured us we could visit as often as we liked, and promised—as if relaying a miraculous dream—that with daily work and staff support, our child might someday, should he survive past infancy, "hold his own toothbrush" and "recognize his own name."

And day-by-day, I shrank back into my crescent of life, loathing my milk-dripping breasts, avoiding the stroller-pushing mothers that haunted my bus stop. On most nights after I'd visited the care center, when melancholy wails and scents of urine and sickness prowled my dreams, I shuddered gratefully for waking, for lucidity. But on the worst

nights, I woke still sensing a newborn's tiny finger clutching my own—then curled howling into my pillow, remembering that *too* was just a dream.

### *Origins*

Following that pivotal, second trimester occlusion, a relentless, seemingly irrevocable process<sup>12</sup> begins obliterating these fetuses' fully formed cerebral hemispheres in utero,<sup>13</sup> flattening nascent brain waves, darkening embryonic dreams. Unfurling its phantasmic wings, hydranencephaly unveils its devastating handiwork—a stark, hollow, fluid-filled cavity where a cerebral cortex should be.<sup>14</sup> At this point, level II (or higher) ultrasound, magnetic resonance imaging (MRI), or intrauterine computed tomography (CT) can confirm a standard ultrasound's diagnosis.<sup>15</sup>

Postnatally, medical professionals most often diagnose hydranencephaly via MRI and CT, less commonly with high contrast agent CT angiography.<sup>16</sup> Health practitioners may also employ electroencephalograph (EEG) readings to confirm a child's lack of higher cortical activity.<sup>17</sup> In hospital settings without available high resolution neuroimaging techniques, physicians may employ light-based transillumination of the skull as a viable neurological screening and diagnostic tool.

Hydranencephalic infants whose mothers received no standard prenatal diagnostic screening may go undiagnosed for months after birth. However, seizures, blindness, stunted growth, paralysis, or excessive cranial fluid accumulation will eventually betray the ruination within<sup>19</sup>.

## Part IV: Dark Moon

### *Echoes*

Raistlin's guardian sat in the dark, stroking tufts of her charge's thick, coal-black hair. It was 2001, roughly three-and-a-half years since that then plaintively howling baby boy had arrived at the special care center. Officially a center "Activity Aid" in 1997, she interacted little with him his first year there, noting only how his head swelled, how his interminable crying vexed the station nurses—"That's just his way," she told them gently. Six months after he reached toddlerhood—a milestone most with his condition never achieved—she became his primary Case Manager. She extolled his assets to the skeptical nursing team, massaged him daily with his favorite toy bowling pin. She marveled as he "experienced" new stimuli, eyes widened, lips smacking. His responses were reflexive rather than cognitive, reminiscent of an oil droplet undulating wildly over the ocean waves without ever penetrating the depths. She showered him with all his state-issued income would allow: a form-fitting pillow, a silky-soft shirt. And when she and her husband failed to conceive, he became her surrogate son. Dreading the phone call she soon had to make, she continued stroking his hair, marveling that she'd never before noticed how beautiful, how soft it was. She absently remembered long gone childhood pets, wondering why she could only bear to pet their fur when they died, never cradle their stiffening bodies.<sup>20</sup>

### *Origins*

While medical textbooks literally define it as a “complete or near complete absence of the cerebral cortex and basal ganglia, which are then replaced by a membranous sac of fluid, glial tissue, and the ependyma in an intact skull,<sup>21</sup>” hydranencephaly, to a suffering child’s parent, means unadulterated loss. The scourge that decimates infant cortex, leaving liquefied brain tissue<sup>22</sup> in cerebral hemispheres’ stead, is the same that eclipses parents’ bright intentions, forces them to mourn their child’s prenatally destroyed future and inability to formulate a thought, to perceive existence—to feel love. It means potential destroyed before it’s even born.<sup>23</sup>

Since, once triggered, hydranencephaly’s path appears immutable, early detection is paramount. Parents receiving early diagnoses may more readily grasp hydranencephaly’s stark prognosis—most children die in infancy,<sup>24</sup> while survivors undergo repeated shunt treatments and potentially complex surgeries designed to ease discomfort and drain excess cerebrospinal fluid accumulation<sup>25</sup>—and explore practical and ethical options.

Functionally, healthcare professionals who detect hydranencephaly in utero may provide parental counseling, prevent labor complications, develop disease management plans, and prepare special pre-delivery pediatric units.<sup>26</sup> Ethically, prenatal hydranencephaly diagnosis affords parents and health practitioners options, but forces them to make excruciating moral decisions. While some medical specialists advise lawmakers to create *specific*

“national medical pregnancy termination guidelines” surrounding pregnant women and their hydranencephalic fetuses—congenital conditions generally incompatible with postnatal life and cognitive function currently satisfy late term pregnancy termination requirements<sup>27</sup>—others debate major *postnatal* ethical issues, such as appropriate treatment options, surgeries, and intervention levels.<sup>28</sup>

Statistically rare, hydranencephalic children remain veritably unknown and unknowable, uniquely isolated in their domain of somatic and cognitive emptiness.

### On the Dark Side

*We named him Raistlin after the brilliant dark sorcerer. The beautiful boy's beautiful name is now cruelly ironic. His reposeful first features belie what comes later—plaintive deaf cries, sightless eyes, bulging forehead, an infant's wheelchair. His world ever silent, ever dark, he absconds from his sliver of life after three years and eight months. While, in my mind, tiny Raistlin remains wrapped in my unsteady young arms—bright eyes, outstretched fingers, rosebud lips, breathing his warmly oblivious, perfect baby breaths—he lies fleshless and alone beneath overgrown grass—in another state, from another life. Engraved on his gravestone, a teddy bear sleeps.*

## Notes

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Zhan, 2013  
Ibid.  
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