

Introduction: Monday, June 21, 2010

It was nearly impossible to stand, but I forced myself to peer into my bedroom. I clutched the doorframe, lightheaded, as my eyes glazed over. It was necessary to focus on breathing.

In and out, I told myself. Come on, Anna Grace, don't stop.

God, I prayed, please don't let me stop breathing.

Something had happened in the previous few days. We'll never know whether it was a relapse of that pesky staph infection or something else, but I believed there was a possibility my kidney disease would win.

Walking to my bed stole the last bit of my stamina, but I had to make sure my purple folder was safely tucked underneath the decorative pillows.

Think, for a moment, of what people have to keep of their childhood and teen-year pastimes. Some have incredible knowledge of sci-fi stories or "mad skills" on a skateboard. Others have high scores on a video game memory card or an array of homemade movies on the Internet. Well, I had a thick purple binder literally filled with hundreds of single-spaced, 8-point font pages about the imaginary characters of my childhood... and the secret "confidants" of my struggles to survive a debilitating kidney disease.

Twenty hours before major surgery, most people would be worrying about dozens of things. I'd act like a normal person later, but not yet. During my last minutes at home, I had to thank God for one of the many gifts that had gotten me thus far: my amazing imagination.

There are so many fears that come with being a chronically ill teenager. My most irrational fear was that if I died, my characters would die, too.

Saturday, June 21, 2003

A Really Cool Adventure

By: Anna Grace Shramere, Age 11

Jobelle woke up. She felt the ground rumbling beneath her.

"It's happening," she whispered, terrified. The people of Mara had talked about it for years, but it was finally coming true. ~~There~~ their

world was ending. Jobelle's mom had talked about it before she had died during that awful miniature earthquake...

"What're you doing?" Todd asked.

I stopped writing mid-sentence and quickly covered the paper with my left hand. "Nothing," I replied.

"Okay," Todd said understandingly. While most little brothers would pester their sisters about a secret, Todd respected my privacy.

"Alright," I said, as if I was giving in after a ten-minute disagreement. "You know how you have your 'imagination'?" I asked. He nodded, likely thinking about his complex group of imaginary friends and stuffed animals.

"Well, I have one, too... except I call it the 'Pretend Friend Association'..."

I thought he'd laugh. I mean, it's fine to have pretend friends when you're in the second grade, but as an eleven-year-old?

"Cool!" He said, thoroughly interested. I felt ashamed for even thinking he'd make fun of me. He was too sweet for that.

"Pepper's one of them, right?"

Grabbing my favorite plush kitten from the top of my stuffed animal bin, I nodded. Todd gently held the hideous tabby, complete with oversized head and beady glass eyes.

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Two days later, Todd and I were hanging out at the local amusement park, which was only a ten-minute drive from our house. We were in line for the mild "runaway mine train" coaster when Todd whispered to me, "Bubba's in the last car. Rochi was riding with him, too, but Bubba threw him out in the tunnel. Now he has to walk to the exit."

I giggled. Nothing new there- Bubba was always pestering his little brother, at least in our imaginations.

Todd was describing his stuffed animal parrot beating up one of his characters, a genius three-year-old toddler lovingly dubbed Rochi. Both existed in actual bean-filled plush toys; however, just as Pepper could, they had the ability to turn invisible. This way, they could "go" where we could.

As the previous riders got out, I glanced back at the last car. "Todd!" I said quietly. "Bubba couldn't have been in the back car! There were two little girls in there!" He looked at me, puzzled. "So?" he asked as our safety bars came down.

He was only eight; who cared if the imaginary world our pretend friends lived in didn't match the real world?

As an eleven-year-old, I did.

The ride started, and as we careened up and down hills, I wondered why I cared. It shouldn't matter. It *didn't* matter- in the words of Todd, "so?" But even so, I began thinking about how my imaginary friends were surviving in the real world. I mean, how did Bubba and Rochi get into the park? Did they jump the fence, or crawl under the turnstiles, or maybe Bubba carried Rochi, or maybe Rochi built a jet pack, and they flew in...

I felt very silly pondering over such a nonsensical thought and even wondered if I might be crazy. But then I thought about my favorite literary characters. Those "people" ... or animals or things... weren't any more real than Bubba, Rochi, or Pepper, but their creators, as authors, had given them a world in which to live. Those characters were nothing without an atmosphere, whether it was based on reality or completely made up, such as an alternate dimension or far away planet. I realized writers must spend a lot of time thinking about how their worlds worked, but they weren't crazy. In fact, they were respected for creating incredible stories that many people cherished.

I had no desire to share my stories, but I was interested in goofing around with my pretend friends just for fun. I'd already been interacting with my cast of characters with or without Todd for years. Why not try to perfect their world- the ins and outs of how they lived, the way books and movies explained everything? After all, not only did I want to have "companions" to keep me entertained when I was bored; I also wanted to have imaginary adventures in places I created.

By the time we were getting off the ride, I decided that as long as it didn't interfere with my real life, it was okay to go on fantasy escapades whenever I got bored. To be a little less weird, I decided to occasionally write down my stories, as if I wasn't actually imagining them in the spare moments of my everyday life, which I secretly was. I had already written a few details and back stories mainly so I wouldn't forget them, but now I also had the ulterior motive of trying to feel like less of a freak.

Wednesday, January 10, 2008  
Prayers for the Kidneys that Hate Me  
By: Anna Grace

Dear God, please heal me completely...

1. Let me not need chemotherapy
2. Please don't let all my hair fall out
3. Take away the acne on my face and legs and arms...  
it hurts and makes me feel ugly
4. Please take away the swelling in my stomach so it  
doesn't feel like I'm being beat up all the time
5. Help my nose, cheeks, and eyelids not be puffy
6. Let my throat not burn anymore
7. Let the confusion go away- it's scary
8. Please fix my kidneys without more medicine
9. Allow me to stop taking prednisone
10. Please give me energy

"Amen," I whispered sincerely, looking up as I finished scrawling in the back of my previously abandoned diary. "Nothing You can't handle, huh? Well, it's a good thing, 'cause there's nothing on this list that I can!"

You'd think I was eighty or something, but nope- sweet sixteen with a special acronym.

FSGS.

Who knew four little letters could change a life?

Never heard of it? No problem- I hadn't either, and certainly couldn't pronounce the mouthful it stood for. Focal segmental glomerulosclerosis means that some of the kidney's filtering parts, the glomeruli, are scarred. This unlucky phenomenon causes nephrotic syndrome: more or less, doctor-speak for "protein in the urine."

Nephrotic syndrome in itself is an awful condition. If a kidney biopsy shows the cause to be FSGS, you're considered especially unlucky. In a bad case of the disease, its process is a vicious cycle. The mysterious FSGS scars the glomeruli, allowing protein to "leak through" into the urine. Our kidneys weren't made for these large protein molecules to slip past the glomeruli, so this intrusion can lead

to end stage renal (kidney) failure if left unchecked for long periods of time. Thankfully, I had been told we had caught my case early.

In July 2007, a routine blood test revealed my cholesterol was 410. There was also protein in my urine. I was referred to the local nephrologists' clinic. In August, I met Dr. Jones for the first time.

"You're amazing," he told me after shaking my hand. "You're losing one-hundred times the amount of protein you should."

*Cool*, I thought, thankful that I didn't have cancer. My mom and I had breathed in relief at that. In the months that followed, I had wondered why Dr. Jones didn't join in our celebration.

As bright and kind-hearted as he was, I had believed Dr. Jones was the worst-scenario type of guy. In retrospect, I simply *was* the worst-case scenario. With that much protein in my urine, I should have been in kidney failure. For reasons medically unexplainable, I'd baffled everyone with disease presentation without kidney damage. Without the urinalysis, there was no indication that I had CKD, or chronic kidney disease, but I certainly did.

The human body is supposed to lose, at the very most, a trace of 0.02 grams of protein per day through the urine. My kidneys were leaking at least 24 grams. To compensate for the lack of protein in my body, my liver was desperately trying to make protein itself. Without that capability, it was making cholesterol.

A corticosteroid called prednisone is the only well-known "treatment" for this monster. There's no cure, and it isn't like prednisone works in every case. If it fails to stop the protein loss, which it does in many FSGS cases, the next treatment steps are completely experimental. My doctor had talked about cyclophosphamide, a chemotherapy drug used to treat a variety of cancers including leukemia.

I don't remember the day I started taking prednisone, but it was sometime during the last week of September. Despite the steroid horror stories you hear, the first month and a half wasn't that bad. My biggest side effects were euphoria, difficulty concentrating, and mild migraines. None of those bothered me too much; what I really hated was the how disgusting the medicine tasted.

I had never learned how to swallow pills, but even if I had, I don't think it would have helped much. Ever bit into an ibuprofen pill and tasted that bitter, metallic flavor? Well, I love that taste compared to prednisone. It isn't coated, so the moment you put it on your tongue, it begins to dissolve.

We tried several methods to hide the appalling flavor. One technique involved crushing the pills into powder and mixing it in orange sherbet or

peppermint ice cream, two foods I can hardly look at to this day. It was so bad that simply the words “prednisone” or “ice cream” could make me feel extremely nauseous. Sometimes it took me as long as three hours to swallow all of the medicine. My record was ten minutes, but that had been toward the beginning, before the side effects began.

The week of Thanksgiving, I started swelling. It sounds crazy, but my entire body felt as if there was someone under my skin trying to burst through. My feet inflated like balloons, and my stomach bloated as if pregnant. To get around, I waddled like a penguin; hence my nickname “penguin” was coined. I became obsessed with the flightless birds of Antarctica.

Eating was difficult, because it only took two bites to make me feel full. I ate less but still gained weight, so my mom called the doctor... daily. Each time, the same nurse would pick up the phone and claim it was “just the prednisone, honey. It makes them hungry.”

I started hating the medicine.

Life got worse in December. My original impressions of this “little kidney condition” changed. I knew it could be dangerous without treatment, but I thought that as long as I took the prednisone, I’d be cured within a few months. As my blood pressure rose along with my weight, I experienced a strange body-wide pain. My heart pounded on a regular basis, and I wondered if this thing could be fatal. I mentioned death here and there, but very few people took me seriously, so I tried to push the thought aside.

I went to school as often as possible, but it was very painful. Sometimes I forgot where I was or how to get around. This wouldn’t have been abnormal, except the junior and senior high building was made up of one short corridor.

After Christmas break, I was determined to stop missing class. I had a waiver from my doctor that granted me leeway from the typical attendance rules, but I believed it was easier to go to school- no matter how agonizing and bewildering- than to stay home. So far, that plan had failed miserably. I did manage to attend on a Monday, but my feet were almost too swollen to walk. When I arrived home that afternoon, I waddled around as little as possible, rising only to go to the bathroom or rotate between my bed and the living room couch.

Writing in my journal was a rare break from the monotony of my new normal. One day, as I pushed my diary back under my bed, I heard the rustling of papers and pulled them into sight. When I saw a familiar name scribbled in my handwriting, I immediately recognized the long-forgotten stack. I grabbed every sheet I could find and headed to our living room couch.

## Monday, June 23, 2003

I was always a “big ideas” type of person, but usually, the big ideas were forgotten by the next day. Not so the PFA!

I had the opportunity to create a country in fifth grade, and I’ll never forget the mix of fun and stress that team project yielded. The good thing about the PFA was it was all mine. No one would see it, except for maybe Todd, so I could do whatever I wanted without grades, deadlines, and teammates to worry about.

Who did I have already? Well, my precious big headed kitten Pepper, of course. Pepper’s personality was set in stone to me. She was curious, had a low voice, loved math, and didn’t love reading. Pepper had some human-like qualities: she spoke English (to an extent), could walk on her hind legs (but usually didn’t), went to “doll school”, and was talented in gymnastics and tap dance. Of course, she had mostly feline instincts. She asked for a specific brand of canned cat food, even though she was capable of eating “human food.” She had learned how to pounce, climb trees, play with yarn, and scratch furniture by watching the real cats of the neighborhood. Dot and Tabby, two more of my stuffed animal cats, had also taught Pepper how to hunt. Being only four or five inches long, Pepper was much smaller than a real cat, so she was limited to game such as imaginary grasshoppers, which she always let go.

With a character in place, Pepper “came to life”... yes, she may have been faux fur, stuffing, and glass beads, but for a few wonderful minutes, I could escape to my own world, where she was a silly, kooky kitten.

*Anna Grace put a bowl on the floor in front of the little kitten. Pepper shouted in a low tone, licking her lips in anticipation of dinner. “Pepper loves food,” the kitten growled, eating sloppily while purring like a lawn mower.*

*Pepper finished within seconds. She leapt up onto Anna Grace’s dresser, using the different drawers as stairs. When she got to the top, Pepper looked out the window and spotted the real family feline outside.*

*“Hi, Brownie,” Pepper yelled through the glass. “Pepper wishes Pepper was real like you.”*

I stopped for a minute. Hmm... that wasn’t a bad idea! I decided right then to let my characters know they were pretend. But in that case, what would their

lives be like? Would they resent being imaginary, or would they like it? It was a mystery I was willing and delighted to explore. I snatched another sheet of paper and began making a list of “rules” that would serve as a guideline for how my imaginary characters would live.

### PFA (Pretend Friend Association) Rules

By: Anna Grace Shramere

Introduction: The PFA is my version of an imaginary world. Everyone’s imagination is different, so there could be a lot of differences between how my pretend world and someone else’s works. To keep things easy for me, I’m going to pretend everyone uses this list, even though they probably do not.

1. It’s all pretend! (If you start to think it’s actually real, you should probably tell someone because that’s not good!)
2. Even if I’m not playing with an imaginary friend at the moment, they are still “living”. (I’m not always going to create every moment of their day, but I’ll pretend their lives are taking place anyway.)
3. Everyone’s imaginary worlds combine. (I know this isn’t really true, but this way, I can pretend there are hundreds of imaginary “people” out there without making them all up.)
4. Imaginary people (“imaginaries”) can be invisible pretend friends, stuffed animals, dolls, and the like. It doesn’t matter.
5. Imaginaries know they aren’t real. Grown-ups and even kids my age think pretend friends are weird or crazy, so imaginaries know they must stay out of the knowledge of the real world.
6. Imaginaries can’t be in the same place as a real person at the same time. If they are sitting in a real empty bench but someone comes and sits down, they must move so they don’t get squished!
7. For every edible real thing in the world (like a can of food), there is an equal imaginary duplicate.
8. Most imaginary humans age normally (if they don’t, it must be mentioned in their introduction.) Stuffed animals have a general age range they stay in permanently; for example, these may include baby, toddler, preschooler, elementary school, preteen, young teen, older teen, college student, young adult, forties, fifties, and so on. (Pepper will permanently be an



elementary school-aged kitten.) Todd's stuffed animals are the exception; Bubba will always be the same age as Todd.

9. Use your imagination! If something doesn't make sense, you can try to make up a theory, but you don't have to! It's just pretend, so everything is possible.

With "rules" in place, I looked at the plush version of Pepper and switched back into make-believe mode.

Pepper went invisible so she could leap through the glass of Anna Grace's windows. She began hunting, but it wasn't much fun. The real grasshoppers ignored her, and the imaginary ones stayed far away.

Suddenly, Pepper heard something from inside a tree. It didn't sound real, like the wind or the birds. This sounded imaginary- and it was the imaginary things that could hurt Pepper.

Crunch, crunch, crunch...

"AAAAAAHHHHHHHHHHHH!" Pepper screamed at the top of her lungs. She leapt back through the window and turned back into her stuffed animal form. "THERE ARE PEOPLE COMING OUT OF THE TREES!"

## Wednesday, January 10, 2008 (Continued)

A lot of people think if you distract yourself from sickness, you'll feel better. It may be true for some people, but for me, no distraction- no matter how exciting- could take away the pain of kidney disease. However, if I was totally focused on something, I would forget that I was sick. The symptoms stayed, but I actually would wonder *why* I hurt.

This was one of those moments. My joints ached as I hurried down the hallway, but I forgot why for a split second. I was holding priceless childhood memories in my hands.

I hadn't written in so long. Life got in the way... high school, band, boys, friends, my hobbies... I remember deciding I had to give it up someday. Sorrowfully, I had stopped towards the end of eighth grade. The PFA had disappeared into the abyss of my room and the depths of my mind. Pepper was the only remaining trace that stayed in my every-day life. She was travel-sized and could come with me everywhere, from school and football games to the nephrology clinic and hospital.

I collapsed on our old red couch and pulled out a couple pages of drawing paper that had been stapled together. The “front cover”, so to speak, had a picture of a little girl in a purple shirt looking out a window. Outside, there was a silly-looking circle with whiskers, eyes, and ears – Pepper as she was depicted way back when – standing next to a tree. I examined my artwork closely and smiled. I couldn’t have been older than eleven or twelve when I made this. I opened it and read...

“AAAAAAHHHHHHHHHHHH!” Pepper screamed at the top of her lungs, running inside and turning into a stuffed animal again. “THERE ARE PEOPLE COMING OUT OF THE TREES!”

Dot- one of Pepper’s guardians- ran outside when she heard Pepper yell. “Pepper,” Dot said. “There aren’t people coming out of the trees!”

“YES THERE ARE! THERE ARE PEOPLE COMING OUT OF THE TREES! THEY’RE COMING TO SEAM-RIP US!”

I laughed, feeling somewhere between amused and embarrassed. I’d read a lot of children’s fantasy books around the time I wrote this, so of course, Pepper was right: people *were* coming out the trees in my story.

One of my favorite children’s books was about another dimension- another world you couldn’t get to except through a special portal or something similar. It was no surprise my first characters came from another dimension, too, but this was my own dimension, nothing like the ones other people had already created.

I continued to read as a young woman, a baby, and a preteen girl descended down a tree and into my backyard. (Pepper ran in a circle, shrieking about “gruesome” ways a stuffed animal could die.) These three characters had escaped from their world, Mara, which was dying. My prednisone mind throbbed as I tried to remember the details of Mara and its circumstances, but I could not. I continued reading as Anna Grace- myself, as strange as it was- invited the group inside through the fantastical window. (Seeing she wasn’t going to be murdered, Pepper got rather bored and left to go destroy a ball of yarn.)

As the woman and Dot talked, Anna Grace observed the three newcomers. The barefoot toddler wore a puffy yellow dress with lilacs embroidered into the fabric. She had short brown hair pulled into dozens of tiny pigtails all over her head.

Anna Grace then met eyes with a frightened human girl. Somewhat petite for her age and very slender, she wore a sleeveless, pastel-orange dress that looked elegant enough to be worn at a fancy wedding. While she kept most of her long brown hair loose, there were two thin sections behind each ear that had been braided and brought together in the middle of the back of her head.

"I'm Ariella Newbrey," the young woman explained. "This is my little sister, Jobelle, and our next door neighbors' daughter, Leah. When everything started falling apart, Belle and I ran. Our neighbor's house had been demolished when the earthquake knocked over a tree..."

"They were dead, and Leah was on the floor crying," Jobelle said in a voice just above the whisper.

"We couldn't leave her," Ariella explained, lovingly bouncing the little girl in her arms. "I grabbed her and we continued. Dad was following us..." She trailed off.

"Dad's probably dead. If for some amazing reason he's not, we're never going to see him again. He won't find us," Jobelle stated, appearing to be in a state of shock. She spoke about death, but it was as if her mind didn't really make sense of what she was saying. Through her expressionless face, Anna Grace could somehow tell Jobelle was very sad and very scared.

*Oh, Belle, my foggy brain thought as I remembered my creation. Jobelle had been my favorite imaginary friend. She was an amazing playmate, despite the fact she wasn't real.*

In third grade, I had switched schools. Although I loved my teacher and classmates, it had been a struggle. I was good at making friends, but the dynamic at the school was different. I didn't have any close friends, so I did the logical thing: I made my own. Jobelle and I were similar, but I purposefully made us a little different as well. She lived through all my biggest dreams... and all my worst nightmares. She had to evacuate her home and lost everything, including both parents, which was something I feared more than anything. At the same time, she could do things I'd only dreamt about. For example, I loved dancing and gymnastics, but wasn't very good and eventually gave up. Jobelle, however, was a protégé at both. When I was alone, Jobelle was there- to read with me, talk to me, play dolls with me... she liked what I liked, for the most part, but even when she liked something I didn't, I was in full control. It wasn't until the summer I was between fifth and sixth grade that I really decided to develop Jobelle's imaginary world. I

gave her a back story, friends, family, and even tried to develop her personality, like an author or screenwriter would.

It was strange I'd felt the need to escape from reality as a child, because my life had been good. I had a seemingly perfect family. Although all families have their issues, I had it a lot better than most of the kids at my school. Regardless, for some unknown reason, I had created this alternate universe in my head, and years later, it had come back to help me.

Now, as a very ill teenager, it was therapeutic to relive what could only have happened in my imagination.

To continue the adventure:

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