

# Funny Face



This publication was supported by a generous grant from the  
National Foundation for Facial Reconstruction (NFFR)



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ISBN 0-9711757-0-5

## Dear Reader

This story has been a bittersweet one for me to relate. Along with our pain, frustration, and disappointment is the amazing support exhibited by the professional community. These medical professionals and their affiliate institutions are not mentioned by name in the telling of this story. FUNNY FACE is strictly Kenny's tale, related by a mother who wouldn't let go when nothing seemed to help.

One organization does stand out in the publishing of this book. The National Foundation for Facial Reconstruction (NFFR) awarded a grant that made it possible for me to share my experiences with you. Without it, you wouldn't be reading this now.

The NFFR provides financial support for the Institute for Reconstructive Plastic Surgery (IRPS) and its patients. Founded in 1951, the NFFR addresses the suffering of the 220,000 children born each year with birth defects of the head and face. Additional funding is offered by the NFFR to thousands more with acquired disfigurements by combining its resources with the talents of the multidisciplinary team at the Institute for Reconstructive Plastic Surgery at NYU Medical Center.

So, to the NFFR, the IRPS, and to all the professionals who have given of their time, talent and heartfelt caring—we thank you for your generosity in making a positive difference in our lives.

Deborah Breslow  
May, 2001

## Thanks also to:

Jay, Robbie, Kenny and Danny Breslow, Marc Breslow, Gloria and Paul Breslow, Florence and David Miller, Jim and Christine Miller, Martha Miller, Ruth and Howard Baker, Midge Boardman, Janet G. Gossard, Dave Collins, Dolores Petrosino, Gina Musumeci, Christine Meehan, Amy Giles, Cher Condos, Jamie Hoff, the women of the "inner circle", Vicky Galow, Patricia McGuire, MD, Rabbi Henry Glazer, and an angel named Janice Pitt.

In memory of Martha Hessel Page, EdD

## A Doctor's Note

I was ecstatic to know that Ms. Breslow had written a book about Kenny's experience. Firstly, because she had done such a wonderfully thorough job exploring every aspect of her son's medical problem. Secondly, because she was willing to share that experience with others—parents, patients, and health care professionals encompassing a variety of specialties.

Historically, medical textbooks and medical school curricula do not adequately educate physicians and other medical professionals in the care of patients with vascular anomalies. Subsequently, many patients are misdiagnosed and mistreated. Misinformation is frequently given to patients and their families. Due to the complex nature of these disorders, any medical establishment with a multidisciplinary team of physicians who share an interest and expertise in vascular anomalies can benefit from patients such as Kenny.

We as physicians have much to learn about the experience a patient with a complicated medical problem and his or her family go through.

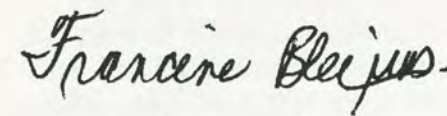
Reading FUNNY FACE reminds us of the child's soul behind the face. Most importantly, it puts us in touch with the day-to-day experiences and emotional turmoil children and families endure.

This work is the result of an energetic mother who was able to channel an incredibly stressful and unrelenting medical and psychosocial problem into a concrete product.

I hope that the readers of FUNNY FACE are as touched as I was by the "voice" of the book and the creative way she presented quite personal and complicated experiences.

I also hope that the readership appreciates how difficult an endeavor Ms. Breslow has so successfully undertaken. It is truly a pleasure to witness the finished product and to have been a part of the process.

Francine Blei, M.D.



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No clinical recommendations for appropriate medical treatment are suggested in this work. This story merely relates the Breslow family's experience with Kenny.

ISBN 0-9711757-0-5

- You and your child will think twice before avoiding eye contact with people just because they look different
- Your child will be comfortable with who he is even if his treating doctors aren't able to fix his AVM
- You and your child will be grateful that you live during a time of continual advances in medicine
- You will appreciate all family members who stand by you, no matter what
- Your child will develop the confidence to overcome staring, teasing or other kinds of exclusionary behavior
- You and your child will always feel you can talk to each other about any feeling that relates to his facial difference
- You and your child will *always* believe in miracles

## The History of My Nose

My name is Kenny. I have a big, red nose. It's not my fault. I was born with it. My mom said it all started while I was growing in her tummy. Mom used to tell all the doctors that she thought my big, red nose was her fault. You see, Mom had to take a lot of medicine before I came out of her tummy so I wouldn't be born too early. But every doctor says the way my nose is has nothing to do with her.

When I was born, my nose was sort of big and sort of red. Now I'm four and it's just big and red.

At first, my red nose stumped the doctors. In the baby nursery, they thought it was a bruise. Then my pediatrician said it was a type of birthmark; she called it a "port-wine stain." Once a lady in Foodtown asked my mom if she drank too much port wine while she was pregnant with me. I don't know why, but my mom didn't answer her.

For the first year and a half of my life, we saw a lot of doctors. But none of them was able to fix my birthmark. We traveled to New York and Boston and Philadelphia to try to find the way to make it better. Mom and Dad were willing to go anywhere. They said they would go wherever we had to go to get help for me, no matter how far away it was.

They asked their friends and everyone in their families, but no one knew anyone who had anything like what I had.

## It's Not Getting Any Lighter

Before Kenny's AVM was diagnosed, he was treated with a laser in an attempt to lighten the redness of his nose, cheek and lip. Sadly, he underwent fifteen treatments from the time he was three months old until he was fifteen months old. But there was no change.

We kept going back for more because we were told that some children required many treatments before there was a noticeable difference in skin color. Each time we went for a treatment, we hoped that "this time" would be "the one" that was a success.

Unfortunately, laser is ineffective for an AVM; the blood vessels which cause the redness are too deep for the laser to reach, no matter how sophisticated the equipment or frequency of the laser.

Laser is effective for specific types of facial anomalies where the blood vessels are close to the surface of the skin.

But we didn't know. We thought we were treating a port-wine stain. For that type of birthmark, laser is medically appropriate and typically effective.

In hindsight, my husband and I feel terrible that we put Kenny through the trauma of so many treatments with no positive end result.

I remember Kenny always being outnumbered in the waiting room. There were at least ten adults to one child. I am certain that an adult can withstand the pain of these treatments much more easily than a child.

Kenny returned for treatments every four to six weeks. I would tell my husband that I wanted to trade places with our son.

Nurses in the Dermatologist's office would have to place Kenny in a papoose that looked like a straightjacket. Then they would strap him onto a board placed on an examining table to insure that he would lie still. I would lay my body over his legs and his dad would lay over his chest and arms so he couldn't move. He was never supposed to move.

The nurse put gauze pads over his eyes so he couldn't see. He was never supposed to see. We wore special goggles to shield our eyes from the laser beam. The doctor assured us that a cooling device was emitted along with the laser to minimize the "sting" to the skin. Nonetheless, during a treatment, Kenny cried in a pitch that sent chills up my spine.

Each treatment lasted approximately two minutes. Two minutes may seem like a short time to most. However, for my husband and me it seemed like an eternity.



The day after a laser treatment, the blisters on Kenny's face looked like cigarette burns. His left cheek and eye were usually swollen shut and his face was covered with ointment to expedite the healing process.

We stopped taking him to public places for at least the first week following a laser treatment because it became impossible to endure all the accusing glares from adults.

Gratefully, Kenny doesn't remember this very well. Sometimes, I couldn't even go into the room to help. I would have to defer to the nurses. I remember feeling guilty about this, but I had my limits.

On laser surgery days, I would cry all the way down the Harlem River Drive. I made a pact with myself that it was okay to cry while driving in New York, but once we got over the George Washington Bridge into New Jersey I would stop. This way, by the time we returned home, no one would know I had been crying.

Those memories will be with us for a long time.

## Finding Dr. B

But Mom and Dad didn't give up. They kept doing lots of research and finally found a "special" doctor called an Endovascular Surgeon.

This doctor is a very important man. People come to see him from all over the world. Some patients are flown in by helicopter! The waiting room is always crowded and sometimes we have to wait a very long time until we get called into his office.

When it's our turn, Dr. B (that's his nickname) comes out of his office and he calls out, "Where's Kenny? Has anyone seen Kenny?" and I say, "I'm right here!"



During my appointments, at least five doctors are always sitting in the room. They take notes about me, but they don't say very much. I like to play with the fire truck that is always on the windowsill. I think Dr. B keeps it there just for me.

Dr. B has a Physician's Assistant. His name is Trevor and he's always nice to me. He takes pictures of all parts of my body (not just my nose) with a special camera he says is a digital camera. Then he lets me sit on a chair and look on Dr. B's computer. You can see my whole face on the screen! Trevor pushes a button to make it bigger and smaller for Dr. B to examine.

I still don't understand how Trevor the Physician's Assistant can have the same name as Trevor the Tractor on my "Thomas the Tank Engine" videotape.

## The Work-Up

The process of getting to the point where we had the correct diagnosis for Kenny was long and frustrating. Throughout the first fifteen months of his life, we met some very kind and concerned physicians who cared very deeply for Kenny and paved the way to our finding Dr. B.

After our first visit to his office, Dr. B ordered two important diagnostic studies: a magnetic resonance imaging study (MRI), essential to separating vascular lesions into high-flow and low-flow types, and a computed tomography scan (CT).

Both studies would give us more information about the severity of Kenny's medical condition and the best way to treat it. He explained that in most cases, young children are sedated for these tests.

These studies also would determine the areas of Kenny's body most clinically involved. In other words, we could pinpoint whether the disease was isolated to his nose or if it went further into other areas of his head such as his eyes, facial nerves, sinus or brain.

Fortunately, Kenny has no recollection of having undergone these studies; he was only fifteen months old. Unfortunately, my husband and I remember them as if they were done yesterday.

It seemed like an eternity before we were given the results.

After a few weeks, Dr. B reported that Kenny had a high-flow arteriovenous malformation of the nose, lip and malar region, but added that Kenny was very fortunate because his brain was free of disease.

In many cases, patients experience neurological impairment if the malformation involves uncontrolled blood supply to the brain.

He said he could help Kenny. He said that even though the medical intervention Kenny had undergone may not have been appropriate for

his existing diagnosis, nothing had hurt him in any way nor would it interfere with future treatment.

I remember how relieved I was.

I knew Dr. B's time was valuable but I had so many questions. "So what are you telling me?" I implored. "Is it really serious? Is it fatal? Is his nose just going to keep getting bigger and bigger and redder and redder? Are you saying he doesn't have a port-wine stain? What do we have to do to help him?"

Dr. B responded calmly. "What your son has is an arteriovenous malformation or A-V-M. An AVM is a tangle of abnormally connecting arteries and veins."

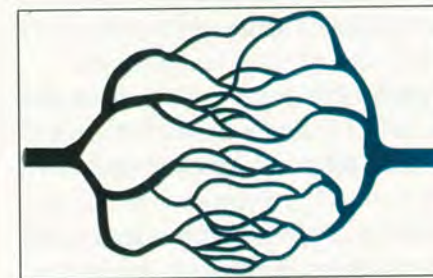
He continued: "As normal vessels course towards the region of the brain they supply, they divide into smaller and smaller branches. By the time they reach their destination, they have branched into many tiny vessels called capillaries. Capillaries have the diameter of a human hair. Normally, there are so many capillaries, blood flow within them is slow and under low pressure.

"In your son's case," he said slowly, "there is no capillary bridge to slow down the flow of blood." An AVM is best described as a high-flow vascular anomaly with multiple, low-resistance shunts which short-circuit the capillary bed."

**Figure 1**

Normal connections between arteries and veins via capillary beds

Courtesy of Target Therapeutics-Boston Scientific



**Figure 2**

AVM-abnormal connections between arteries and veins that exist without capillaries between them

Courtesy of Target Therapeutics-Boston Scientific



He said that Kenny's nose was so red because of the accelerated pressure of blood supply feeding the malformation. The excessive supply of blood forms a sponge-like reservoir.

If the AVM was not controlled, he said it would become more saturated with blood and the bulk to his nose might increase.

He said we had to control this flow of blood to decrease the bulk to his nose and to prevent any harmful effects to either the underlying tis-

sue or growth of the nasal bone. Just hearing “we” assured me that my husband, Kenny and I were in a partnership with Dr. B. I began to breathe again.

Just hearing “we” assured me that my husband, Kenny, and I were in partnership with Dr. B

AVMs are very rare. They can grow in different places throughout your body such as your brain or your spine or your stomach. If the AVM is in a part of your body where it can't be seen, you might not even know you have one. Severe AVMs not treated in time

can be very serious, even fatal.

Only a small number of people have an AVM somewhere on their face. Even fewer have an AVM on their nose. Dr. B did not quote statistics about nasal AVMs, but said that the number was very small.

We talked about next steps. He encouraged me to process everything we had discussed and talk it over with my husband.

Then we scheduled an appointment to consider possible methods of treatment beginning with an arteriogram.

I realized that I was getting overwhelmed, so I thanked him, confident that we were in good hands.

## Quit Staring at Me

For a long time, I didn't even know that my nose looked different 'cause I was too small to look in the mirror. Also I couldn't talk so I didn't understand the questions that strangers asked my mom and dad. Back then, it didn't bother me when people stared. After all, don't people always stop to look at babies?

One time, Mom and I went to the mall. She was pushing me in the stroller. Some man asked her, “Wow, what's wrong with his face?” “Nothing,” my mom said and she sounded mad. “What's wrong with yours?”

The man looked very cross and the next thing I knew, Mom was pushing my stroller really fast toward the parking lot. I thought it was fun.

When we got in the car, Mom strapped me into my car seat. “I'm sorry that we had to cut short our trip to the mall,” she said. Then she sat in the driver's seat and cried.

Before we knew Dr. B, we went to a lot of different doctors so they could look at my nose. Sometimes, ten doctors would be in the room at the same time. They asked my mom and dad a lot of questions.

Mom said that some of the doctors looked young enough to be her

own kid! They would touch my nose and ask me if it hurt. They would take pictures but I would never sit still. They always seemed like they were mad because I didn't do what they told me to.

Two times, a doctor put a long tube down my nose. I didn't like that. Mom had to hold me really tight to keep me from squirming out of the chair. (That was called a nasal endoscopy.) I hope I don't have to have that test again for a long, long time.

## Re-Entry

Mommy never shows her true feelings about my nose. I heard Grandma say that if she would just talk about it, she would feel so much better. “Pain shared is pain lessened.”

I never know about a test or operation until right before it happens. Mom says she does this on purpose so I won't be scared beforehand.

This is how it usually goes:

It's really early in the morning and I'm in my bed sleeping. Mom or Dad comes up and wakes me, “Kenny, Kenny, we have to go now.” Still half-sleeping I ask, “Where are we going?” “We're going to New York to the doctor,” Mom says, putting my slippers and jacket on and leading me into the bathroom to go pee pee.

Then it's always the same. I start screaming and crying, “I don't want to go to the doctor” over and over and over.

Mom sits in the backseat of the car with me and tries to distract me: “Look, we're on the top level of the George Washington Bridge!” “Wow, I counted ten taxicabs already!” “Boy, these buildings are tall!”

Before you know it, we're there and I usually stop arguing.

As much as I don't like being surprised, at least I don't have to spend time thinking beforehand about what's going to happen. I'm sure I wouldn't sleep at all.

Mom tells her friends on the telephone that she doesn't prepare me for these hospital trips on purpose. “Why should he have to worry before we get there? It's bad enough that we do.”

After an appointment, test or operation, coming home is always hard for Mom and Dad. You'd think they'd be excited to be out of there. I sure am! One time, we were pulling into the driveway after a trip to the hospital. Mom thought I was asleep in the backseat, but I heard her say to Dad, “I wish we could quietly exit the car, tip-toe up the stairs, get into bed and collapse for the rest of the week.”

Not me though. No matter how upset I may have been at the hospital, once we are home, it's over. I never let it ruin the rest of my day.

When we walk in the door, my big brother Robbie always seems happy to see me, but he looks like he missed out on something.

He and I do everything together so after I've been away for a day or a few days or a week, even if he's come to the hospital to visit me, I know he feels "left out." Lately, Robbie has come along to a few of my appointments with Dr. B. Now I'll bet he doesn't feel he needs to come again.

Usually our babysitter Gina or Grandma or Papa is here watching Robbie and Danny, our baby brother. Whoever is babysitting always



stays and visits for a while so I get to be with them too.

Sometimes Mommy will say to Grandma or Papa, "You can go now if you're tired." But they always stick around to play with me.

It's funny, Robbie thinks he's missing out on whatever I'm doing in New York and I think I'm missing out on whatever he's doing back at home.

Mom says "the grass is always greener on the other side." Funny but I don't think I've ever seen grass at the hospital.

Everyone always seems worried when I go to the doctor. But Mom and Dad don't tell everyone very much. Mom says they need time to process what they've learned.

Daddy returns to whatever is left of his workday. He has missed a lot of work because of my nose. One time, Mom told him that if he really couldn't miss another day, she could handle the appointment on her own. "No way," he said. "We are all in this together." Mom smiled. She was happy about that.

My mom and dad always take a tape recorder to my appointments so that everything the doctor says to them can be taped. I heard Mom tell her best friend, "Sometimes when I am especially overwhelmed, I go into a trance while the doctor is talking. It may seem strange, but that's how I cope."

I don't know what she meant, but it sounded important.

Mom and Dad depend on that tape if they forgot something important that the doctor said.

One time, I was walking by Mommy's room while she was listening to one of the tapes.

She had the sound on real loud and was taking notes. I heard Dr. B's voice coming from the tape recorder then I heard myself playing with a toy in the background. You could barely hear the doctor talking 'cause I was making so much noise, "Vroom, vroom!"

## Where My Nose Takes Me

I get a lot of nosebleeds. One time I had a really bad nosebleed at preschool. My teacher held me tight on her lap and the lady in the office held gauze on my nostril for almost an hour. (I only know that because I overheard the lady in the office telling my mom on the phone how much my nose bled.)

Another time, my nose bled so much that I had to go to the hospital in an ambulance with my babysitter Gina and my big brother Robbie. The ambulance driver drove really fast and when we got to the Emergency Room, Mom and Dad were at the front door. I was so glad to see them.

There was blood all over my fire truck shirt. Mom and Dad were shaken and upset but they said it wasn't because my shirt was ruined. I couldn't wait to tell everyone at preschool that I got to ride in an ambulance.

Mom and Dad said I was very brave.

After the Emergency Room visit, we drove over to a doctor in New Jersey who treats me some-



times. He is called an Otolaryngologist. He sees kids who have problems with their ears, their nose or their throat. Mom says we have to see him so that in case we need a doctor and can't get Dr. B, we have another doctor who knows about my nose.

Dr. R could see that Mom and Dad and me were upset about my nosebleed. He asked me if he could look up my nose to see where the blood was coming from. I wasn't too happy about it but I said it was okay.

He had to put the long tube down my nose. I screamed and cried. After all that, he wasn't even able to see where the blood had come

from because it was already a few hours since my nose was bleeding.

I kept crying and he said he was sorry and didn't mean to hurt me.

He told Mommy to keep using a vaporizer in my room and gave us a spray for my nose to keep it moist.

I'd say we are pretty used to nose bleeds around here so we don't get too scared when they happen

The next morning there was blood on my pillowcase and on my face. I went downstairs and showed Mommy the blood. She washed my hands and told me that it was nothing to worry about. I made her change my pillowcase right then and there.

During breakfast, I asked Mommy why the doctor in the Emergency Room didn't fix my nose. She said that one visit to the hospital or to the doctor was not going to fix my nose.

She said it might take some time for all my doctors to figure out how best to treat my big, red nose. She promised me that she and Daddy and all my special doctors were doing everything they could to find the best way to help me. She asked me if I could be patient. "What does patient mean?"

I still get nosebleeds pretty often but I'm used to them now. Just this past week, I had a nosebleed everyday for the whole week! Dr. B says it's common for children with AVMs to have frequent episodes of epistaxis. That's the fancy word for nosebleeds. I don't think I'll ever pronounce it right.

If Mom is not able to help me right away, I can even hold the gauze on my nostril myself. Then my Mom takes over.

I want to feel like I can help too since it is my nose.

I'd say we are pretty used to nosebleeds around here so we don't get too scared when they happen.

One time, Robbie said, "Mom, nosebleed," just like he was telling her that a videotape was over and needed to be rewound.

## Kenny Breslow? Please Come In

Kenny's case has been presented several times at medical conferences called Vascular Anomalies Clinics. The four that we've attended have been held at major teaching hospitals in New York and Boston.

Physicians encompassing a variety of medical specialties including, but not limited to, Vascular Surgery, Dermatology, Plastic Surgery, Otolaryngology, and Interventional Radiology are most likely to participate in these conferences.

Although we know the goal is to support Kenny in his treatment plan, my husband and I have not enjoyed subjecting him to the "conference experience." As a rule, they tend to be impersonal and somewhat violating.

Kenny is never happy about being presented at conference. When he was quite young, he didn't understand. Now, it's a different story. Kenny is very intimidated by the audience of physicians in the room, most of whom we have never met.

Even though it can be unpleasant, we explain to Kenny that we do this so all the doctors who know the most about AVMs can put their heads together to determine the best way to help him.

A Vascular Anomalies Conference offers parents the unique opportunity to have their child's case reviewed by a group of subject matter experts in vascular anomalies. This multidisciplinary team will offer a variety of treatment modalities for your child, some which may not have been considered by your child's treating physician.

Although it's hard, we know the benefits we reap from the conference outweigh our moments of discomfort

The benefit of face-to-face contact with this team is very important. Seeing the patient in conjunction with his or her medical reports gives the group a complete picture of your child. Although it's hard, we know the benefits we reap from the conference outweigh our moments of discomfort.

When Kenny asks us why we've had to go to conference more than once, we remind him that as he grows and his AVM changes in size, contour and color, it helps the different doctors to understand more about his puzzling AVM.

An added bonus is that the treatment recommended for him may also help other children who have similar diagnoses.

The waiting room is filled with kids who have a big red nose, forehead, chin, lip, cheek, eyelid, neck or scalp. Parents and children all look



at each other but rarely ever talk to each other. I suppose we're all nervous about the outcome. Sometimes the adults try to converse in a feeble attempt at camaraderie.

Most of the doctors in attendance don't smile or introduce themselves. I've explained to Kenny that they don't joke around because they are very serious about trying to help him.

We know that it's critical for them to obtain as much information as possible about Kenny within a short period of time. The entire conference is only two hours.

We also are aware that other children are waiting to be presented. The doctors must come to some sort of consensus about each child's case before the conference is over. It is a very important session for all the patients on the docket.

*One day, after a particularly draining appointment, I overheard Kenny tell his brother, "My nose causes a lot of commotion."*

As overwhelmed as I am sitting in the front row practically knee to knee with at least one or two doctors, I do my best to provide the group with a brief, factual review of Kenny's current medical status and to raise any issues we are concerned about.

I try not to be intimidated by the size of the group or the fact that I know so few of the physicians. One doctor always makes an effort to smile at me, which I find most reassuring.

She is Dr. F, a Hematologist who organizes a support network for parents of children with a variety of facial anomalies. The group meets monthly and many times hosts guest speakers. It is a positive and cathartic experience for all in attendance.

Not all Vascular Anomalies Conferences require that the patient and his family be included. Some institutions present cases utilizing the child's films, photographs, and notes provided to them by the treating physician.

Kenny's case has been presented in both ways—with him present and absent.

At one conference, my husband looked as though he was going to cry when a doctor put a stethoscope on Kenny's nose to listen for blood flow. He may not say a lot but he is clearly affected by everything Kenny has been through.

When I am feeling sad or overwhelmed, I pick up the phone and call a friend or close family member.

We have utilized the Psychologist who is available for counseling craniofacial patients and their families. She is adept at providing us with

responses to consider when we are confronted by people who are curious and want to know more about Kenny's nose.

Although our sessions are helpful, I don't think my husband feels as comfortable sharing his feelings.

Sometimes it's hard not to wear our emotions on our sleeves. And Kenny is a smart kid; he senses our distress.

One day, after a particularly draining appointment, I overheard Kenny tell his brother, "My nose causes a lot of commotion." I didn't know he knew that word.

## What! More Spots?

*My nose isn't the only part of me that puzzles my doctors. I have at least fifteen red spots on my arms, neck, tummy, back, leg, face and ear. I can't see the ones on my back and neck but I heard Mommy tell Dr. B they are "all over the place." Dr. B told us to go see a few different skin doctors (Dermatologists) to see if we could get more information about my growing spots.*

*Each doctor said they weren't sure whether they were AVMs like my nose, so they called the spots superficial vascular lesions.*

*Some of the spots are the size of a pinhead and others are as big as a dime. They don't hurt me and they're not big and red like my nose. I wouldn't have even noticed them except once when Robbie put a sticker on my hand, I saw one. I told Mommy I had a boo-boo.*

*Mommy and Daddy talked with the skin doctors, with Dr. B and with the doctors in Boston that we visit sometimes. No one knew exactly what the spots were. They all told Mommy I should have a special test. They called it a biopsy.*

*When we told Dr. B what all the skin doctors said, he sent us to see a Plastic Surgeon. His name is Dr. Z.*

*Dr. Z has a fancy office. No fire trucks to play with there. He has beautiful pictures from all over the world in his waiting room. Even in his office where he checks me, Mom says the couch and chairs look like they should be in a museum!*

*When we went to see him for the first time, Mom could hardly pay attention to what he was saying because she was so afraid I was going to break something.*

*After he touched my nose for a while (every doctor does that when they see me for the first time), he told me I could go into the waiting room with Grandma Florence so he could talk with Mom and Dad. I didn't want to leave Mommy but he gave me a lollipop so I left.*

I figured it was like when we are home and have to use the potty. Mommy always tells us to close the door so we can have privacy.

Dr. Z spoke with Mom and Dad for a long time. He called Dr. B and shared his ideas on a speaker phone. I know because I could hear him talking from the waiting room!

When Mommy came out, she went to the receptionist to set up the special test at Dr. B's hospital.

I like to play hide and seek behind the pillars in Dr. Z's waiting room. The receptionist doesn't mind because she has a daughter my age. Dr. Z calls me a "vilda chaya." Mom says that means "wild and full of energy!"

Dr. Z explained that when we met at the hospital, he would be taking samples of tissue from my nose and my shoulder. I told him Mommy had tissues in her pocketbook. He smiled.

Then he explained that he would take my skin tissue, soak it in some special water, pack it in a special jar, and send it in a special package to a doctor in Boston.

He called this doctor a Pathologist. It was really hard to understand everything that was going to happen to me but I knew Mom was listening and she understood. That was enough for me.

A few weeks later, we met at Dr. B's hospital for my biopsy. I was asleep when Dr. Z took off the samples of skin so I don't remember much about that day. I know it happened because when I woke up, I saw the scars on my nose and my shoulder.

When the skin samples "specimens" were tested in Boston, the results were sent to Dr. Z in a letter called a Pathology Report. The report said the new spots were also AVMs.

I sure hope these spots don't get big and red like my nose! I told Mom to ask Dr. Z if the new spots were going to grow big like my nose.

"No one can predict whether they will or won't," Dr. Z told Mom. "For now, we have to keep the focus on his nose; we'll keep watching the new lesions."

## Funny Face

Now I'm old enough to look in the mirror. I'm old enough to notice that a lot of people stare at me. I'm old enough to understand the questions that nosy grownups ask Mommy. I know when the children are laughing at me. I hear when they whisper things to each other about my nose that aren't nice.

Mom always tells my brothers and me that it's not nice to stare. She says that people don't mean to stare at me. She says they're just



curious and want to understand why my nose is big and red. I told her I don't like the "big nose" word and I don't like the "birthmark" word and I don't like AVMs. AVMs make me sad.

Mom and Dad say that it's okay to tell kids if it hurts my feelings when they make fun of my nose. Mom says that every mom and dad knows the rule:

It's not nice for one kid to tease another kid just because he looks different.

I guess there are moms and dads who sometimes forget to tell their kids that rule.

My brother Robbie calls me Funny Face. I don't like

when he says that but I know he doesn't mean to hurt me. He is always there to protect me from the kids and grownups that say mean things or ask nosy questions. I figure sometimes he gets tired of always having to stick up for me.

My preschool teacher told my mom that maybe Robbie calls me Funny Face so the other kids won't have a chance to call me something even meaner.

## Hospital Stays

To date, Dr. B has done five microsurgical procedures called transarterial embolizations on Kenny's nose. Only a few doctors in the world have the technical skill to perform this surgery safely and effectively.

The procedure begins with an arteriogram. An arteriogram provides a map of Kenny's vascular system (blood vessels, capillaries and arteries). This "mapping" is a critical diagnostic tool and provides Dr. B with the information he needs to determine how best to treat the AVM.

A very thin, flexible tube called a catheter is introduced into an artery (usually at the groin) and then advanced through the blood vessels of the body to the arteries supplying the AVM. This is performed in an angiography suite using x-rays to see the position of the catheter.



A liquid called contrast, which can be seen on x-rays, is injected through the catheter and x-ray images are obtained. This gives detailed pictures of the location, size and shape of the AVM as well as a map of the arterial tree from which it arises.

The angiogram helps Dr. B decide which vessels must be sealed to stop the high flow of blood. He seals or burns the lining of the vessels using special materials called embolic agents that usually consist of one or a combination of the following: particles, coils, glue or alcohol.

Multiple embolization procedures may be necessary to completely block off the AVM, or to block off as much supply as possible to keep it under control.

He calls this surgery "angio-embo" for short.

## Scary Stuff

Before my first "angio-embo," I heard Dr. B tell my mom and dad four things:

1. There is no cure for an AVM.
2. There is no guarantee the operation will make my nose look any less red or any less big.
3. The surgery can be very risky.
4. AVMs don't grow

Other doctors said:

1. "If these things are left untreated, they can grow out of control!"
2. "If you tamper too invasively with an AVM, you can wake up the monster!"

I wonder if I really have a monster in my nose. If I do, I'm not telling anyone (except maybe Robbie).

Even though we've been told that AVMs don't grow, mine does. I guess my case is different. Dr. B said that my case is an exception. He says, "Kenny, your nose continues to puzzle me."

He explains to Mom and Dad that at least for now, there are no other known options for controlling my nasal AVM.

That's why Mom and Dad have decided to go ahead with the operations. They really trust Dr. B. They believe that if he knew of an easier way to treat my nose, he would tell them.

Whenever Mommy tells me that we have to go to the hospital for another operation, I get very sad. I don't like that silver table in the scary room with the big machines. I don't like that mask that they put on my face to put me to sleep, even with the grape chapstick they rub on the edges to make it smell good.

I don't like the pin they stick in my hand and in my arm. One day, on the way home from school, I asked Mommy, "Do you like when a person sticks a pin in your arm?" "Kenny!" she said, "what kind of a question is that? Did anyone ever stick a pin in your arm?"

"Yes Mommy, AT THE HOSPITAL, remember?" She was quiet for a minute, "It wasn't a pin Kenny, you're talking about the intravenous needle."

Whatever it is, I hate when they put that needle in my hand. It hurts me. I don't like that board they tape to my arm so I can't pull at the medication lines. I don't like that tube they put in my penis to go pee-pee. I always try to pull it out and the nurses get mad.

I don't like that cuff on my arm that gets really tight every ten minutes (even in the middle of the night). It always wakes me up. The nurses try to make it sound like fun. "Time to give your arm a hug!"

I don't like that little black cuff they put on my toe either - even if it does light up.

Most of all, I don't like that blue identification (ID) bracelet they make me wear. One time, a nurse put the bracelet on my stuffed dog, Duke. She pretended it was his new collar.

I cried really hard and made her take it off.

I don't understand why that bracelet is so important. None of the nurses ever lets me take it off. I guess they are afraid I might get

lost. I'm hooked up to so many wires and tubes and monitors, I'm not going anywhere.

I told Mommy that I don't like going to the hospital because I don't like them to do anything that hurts me. I told her to tell Dr. B that I don't want to go anymore. She promised she would.

After they take a lot of the wires and tubes off me, I get to move from the ICU to "the floor." Mom told me "the floor" is the regular Pediatric Unit. If you are doing pretty well, the nurses usually take off some of your wires and they don't have to stick you as often.

The playroom is at the end of the hall on the tenth floor. I know when I'm well enough to go to the playroom that I'm almost ready to go home. All the kid patients go there if they can. It beats staying in your room! Some kids are in wheelchairs. The ones who are still on IV medicine have to bring their IV poles with them. Most kids have lots of bandages on them.

Some kids can go to the playroom in their own clothes. But a lot of kids have to wear hospital gowns.

At least half the kids in the playroom don't have any hair. You can see the scars on their heads from operations they've had on their brains.

No one ever really knows what's wrong with me; I can tell by the way they look at me. I figure they think I have the same problem as them. Or maybe they just figure that for some reason, I have a swollen, red nose.

Anyway, no one looks at my nose funny in the playroom. In the playroom, I'm just Kenny. Mom says that when we're in the playroom, we're not so "unique".

I drew a picture and the lady in the playroom put it up on the wall with the other pictures. The ladies in the playroom know all the kids really well. I take my naps on the couch in the playroom. Mom drinks a lot of coffee there.

## We're All the Same

Dr. B says I'm special. He says that's what I should tell kids when they tease me about my nose. I don't think I feel right saying that though. I don't see anything so special about having a nose that's bigger and redder than every kid I know. But I know he is just trying to help.

The way I see it, I'm not so special. I'm pretty much the same as every other kid my age. I like to play with trucks and trains. I like to



dress up in my firefighter uniform and pretend to put out fires. I like to wear hats. Mom says I have a hat for every possible situation.

I like to go to the park and have Daddy push me on the swings. I like to go to the beach and fill my bucket with water for sandcastles. I like to take the train to Hoboken with Papa David and Papa Paul. I like to go fishing with Uncle Howard. I like when Grandma Gloria makes chocolate pudding. I like when Grandma Florence tells the story about "Junior Fire Chief Kenny Saving the Day."

I like to take bubble baths with my brother Robbie. We splash each other and get water all over the bathroom floor! I like collecting Dalmatian animals with my babysitter Gina.

I make Mommy lie with me in bed before I fall asleep. We follow the same routine every night:

- We get cozy under the covers
- We read a book story
- We tell a "make-up" story
- We sing a song
- We talk about my day
- We say that everything is going to be okay with my nose

My mom wrote a song for me that she sings at night called "The Kenny Song." Sometimes, that's the song she sings before the mask puts me to sleep at the hospital.

I know I'm safe in my bed with Mommy and Daddy and of course, Duke.

## Feelings

Sometimes, while driving in the car, I watch Kenny in the rear view mirror. After a period of quiet, I'll ask, "What are you thinking about Kenny?" He always responds in the same way—"Not anything."

Every time he gets pensive, especially in the car, I automatically assume that he's thinking sad thoughts about his nose. But I'm usually proven wrong. Most of the time, he's really not thinking about anything.

Except for yesterday. We were driving to school and Kenny asked, "When something gets old, do you have to get a new one?" I looked in my rear view mirror and could see that he could see himself. "It depends on what kind of a thing you're talking about. Cars, refrigerators, and other appliances need to be replaced when they get old and worn."

"Was there something specific you were referring to?"

"My nose," Kenny said. "My nose is old." "Why do you think your nose is old?" I asked, "Because it's red."

I try to encourage Kenny to put his feelings into words. I validate that it's okay for him to feel angry about what he's had to go through. I admit frequently that Daddy and I feel angry too. But I make it clear that it's not him we're angry with – it's the situation.

"It's been a lot to endure," is my daily mantra, "and there's a lot more ahead of us."

It is important for my husband, Kenny and me to remain prepared for the uncertain progression of Kenny's condition. This allows us to set realistic expectations for what may be in store.



"I wish it were different for you Kenny," I've said so many times. "I wish it were easier for you and for me and for Daddy and for our whole family. Life gives us challenges so we will be stronger, as individuals and as a family.

"Some people go through their whole lives without ever experiencing adversity. We are facing more than most, but we'll be better for it."

I'm sure at some point Kenny tunes me out. At four, he can't grasp all of my philosophies.

However, I do know that he is secure because of parents, grandparents, aunts, uncles and siblings who are so loving, understanding and supportive.

## Sharing

I talk with Mom and Dad about how I feel about my nose. I tell Mom to tell the kids that I don't like when they say mean things to me. Sometimes, when we go somewhere I've never been and I'm going to meet new kids, I hide behind Mom and tell her I don't want anyone to see me. I get scared that kids might not want to be friends with me because of my nose.

"There is nothing to ever be afraid of," Mom says. "There are so many reasons why someone would want to be your friend, Kenny. You are fun and friendly and kind and imaginative and smart and sensitive. There isn't anyone who wouldn't want to have a friend like you."

She tells me that when kids are focusing on how I look and they can't seem to get past my nose, I should:

1. Take a deep breath
2. Smile
3. Introduce myself

And say the following:

"I know you probably wonder why my nose looks the way it does. I bet you think there's something wrong with me. But I'm really fine! It's just a birthmark on my nose that I was born with. My doctors are doing everything they can to help me.

"Why don't you try getting to know me? I'm really a nice kid."

I made a promise to Mom that I would do the best I could. Some days will be easier than others. But I'm willing to give it a try.

After all, there's more to me than just my nose.

I try to encourage Kenny to put his feelings into words. I validate that it's okay for him to feel angry about what he's had to go through.

## The Future

Interventional Radiologists, Endovascular Surgeons, Neurosurgeons, Plastic Surgeons, Hematologists, Otolaryngologists, Dermatologists, Geneticists and other members of a craniofacial medical team are constantly researching new treatments for AVMs.

To reduce the redness of a child's nose, cheek, lip, chin or other part of the face or neck, a camouflaging make-up can be applied every day, but that's more for a girl.

At some research institutions, doctors and scientists may find a new or existing medication that will control or even cure AVMs. There are clinical trials being considered and approved for children every year that may offer a less invasive approach to treating facial anomalies.

There is even a surgical procedure that may lessen the bulk and improve the contour for a child with a nasal AVM. It's called a nasal resection or surgical debulking. In Kenny's case, the location of his AVM makes it critical that such a procedure be done with particular care and skill.

In Kenny's case, it is impossible to resect his entire AVM because that would mean removing his whole nose.

To insure the best cosmetic result, the resection of a nasal AVM is performed by two specialists. The first is a Plastic Surgeon. He is an expert in making an opening in the skin called an incision so he and the other surgeons can visualize the underlying tissue.

The Head and Neck Surgeon then looks inside the incision and takes out or resects as

much diseased tissue as possible. This procedure is done only by an extremely skilled doctor who knows a lot about AVMs.

He will insure that the resection is done as carefully as possible so that normal skin tissue remains unharmed.

Following the resection, the Plastic Surgeon is responsible for closing the incision to insure that the child is not left with an unsightly scar on his nose.

Since there is always a chance of excessive blood loss with this type of surgery, an Interventional Radiologist or Endovascular Surgeon will perform a pre-operative embolization to seal off as much blood flow as possible.

In Kenny's case, it is impossible to resect his *entire* AVM because that would mean removing his whole nose.

However, my husband and I have already consulted two physicians who are willing to attempt a *partial* resection; with the goal of removing as much diseased tissue as possible without destroying skin.

We met with Dr. S, a Plastic Surgeon and Dr. P, a Head and Neck Surgeon. During the consultation, we discussed the resection; including its many drawbacks. "This is not a cure for your son," they warned. And we understood. It's a temporary measure, really – a chance to get his nose looking as normal as possible so he might be able to avoid the harmful teasing that is typically associated with kids who look different.

We all agreed that if we lived in a society where people were more tolerant of those who looked different, it probably wouldn't even be necessary to consider such a procedure.

But unfortunately, we have to expect that Kenny may endure some tough times should his nose remain looking the way it does now.

When we discussed it with Kenny, he suggested innocently, "Why don't you just put my nose on a diet?"

## New Noses

When I am a teenager and my nose is all grown, I may be able to have it fixed. I can't imagine how hard it's going to be to "build me a new nose."

Sometimes I ask Mommy if I can look in her make-up mirror. I look close at my nose. I know it's big and I know it's red. After the hospital, Robbie always asks Mommy and Daddy how come they didn't take off my birthmark. Mommy always explains that it's not something you can take off. She says the doctors know what to do and whatever they do, they have to do it slowly and with good reason.

Even though I believe Mommy, I wish they could do it faster. That's why I always ask the doctors, "Are you going to fix my nose today?"

They always smile and say they wish they could. I know everyone is trying. I do. I know they care about me and I know they care about my nose looking "as good as possible."

For now, I will look to Mom and Dad to take care of my medical care. I will trust that the doctors who care for me now and in the future will always do whatever is safe and whatever is best for me.

In the meantime, I will try to be brave. It's really hard when people make fun of me, but I try to remember what Mom says, "Look at every challenge you experience with another kid as a chance to learn something".

Sounds good, doesn't it?

Maybe in my lifetime, doctors will find a cure for AVMs. Until then, I'll just have to accept my funny face.

## Tips For Parents

The process of recognizing that your child has a facial anomaly, accepting it, seeking medical guidance and becoming an expert with regard to your child's particular anomaly is, at best, exhausting.

You *will* be told at least one of the following by well-meaning friends and relatives:

1. Be grateful that he doesn't have \_\_\_\_\_ [Fill in the blank].
2. Tell me about it. When Susie had her tonsils out...
3. Give it some time, it'll probably go away on its own.
4. Don't you think you're coddling him too much? You do have two other children to think about.
5. Maybe you're making more of this than you need to.
6. He's a child of God.
7. Go out and have a few drinks and forget your troubles for a night.
8. This too shall pass.
9. You are a saint. I could never do what you are doing.
10. God chose you as the parent for this child because you are so [strong/patient/kind/compassionate/sensitive/smart/resourceful/ unselfish/giving \_\_\_\_\_ Fill in the blank].
11. Are you sure you are with the right doctor(s)?

The response to all of the above is simple and has proven successful for all members of our family during the past four years. It goes like this:

"Thanks very much for your concern." Period.

## Final Thoughts

Most people *do* mean well, especially those who truly care about us. No one likes to see people they care about face difficult times.

What separates us from others is that unless one has experienced a medical situation identical to ours (which is unlikely since facial AVMs are so rare), it becomes difficult to accept such comments as genuine.

The best advice my husband and I can offer is, try not to have expectations of others. Communicate openly, using the professional resources your physician and all members of the health care team make available.

Seek out support and advocacy groups for craniofacial anomalies. They're out there! They can help you make sense of your child's diagnosis and prepare you for the emotional roller coaster that may lie ahead.

## Suggested Reading

Children with Facial Difference: A Parent's Guide  
By Hope Charkins, MSW

Arthur's Nose  
By Marc Brown

The Okay Book  
By Todd Parr

Just Because I Am: A Child's Book of Affirmation  
By Lauren Murphy Payne, MSW

Why Am I Different?  
By Norma Simon

Conversations with God—an uncommon dialogue  
By Neale Donald Walsch

Autobiography of a Face  
By Lucy Grealy

Strength, Courage and Confidence: What Facial Difference Teaches Us  
By Jennifer Wallace

## Helpful Websites

[www.aboutface2000.org](http://www.aboutface2000.org)

[www.bethisraelny.org/inn](http://www.bethisraelny.org/inn)

[www.childrenshospital.org/vascularanomalies](http://www.childrenshospital.org/vascularanomalies)

[www.nffr.org](http://www.nffr.org)

[www.irps.net](http://www.irps.net)

[www.hnline.org](http://www.hnline.org)

## Acknowledgements

We thank the following medical institutions, research and educational centers, support organizations and individuals for helping us and for taking such good care of Kenny:

Rickie Anderson—AboutFace USA; The Barnert Temple Preschool and Family Center; Alejandro Berenstein, MD—Beth Israel Medical Center—Singer Division, Center for Endovascular Surgery; Francine Blei, MD—Stephen D. Hassenfeld Center for Cancer and Blood Disorders, NYU Medical Center; Patricia Brous, MD—Beth Israel Medical Center—Singer Division, Department of Anesthesiology; Teresa Buchanan, RN, MBA, Patricia Burrows, MD, Jennifer Marler, MD and John Mulliken, MD—Children's Hospital of Boston—Vascular Anomalies Center; The Englewood Hospital and Medical Center—Dr. Walter Phillips Health Sciences Library; Forward Face; Maria Garzon, MD—Columbia Presbyterian Medical Center, Department of Dermatology; Dr. Louise DiGia—Family Chiropractors of Ridgewood; The Laser and Skin Surgery Center of New York; New York University Medical Center—Institute of Reconstructive Plastic Surgery (IRPS); The Meland Foundation for Family Education; Mary Madrid, RN, PhD—Beth Israel Medical Center—Singer Division, Center for Endovascular Surgery; The National Foundation for Facial Reconstruction (NFFR); Mark Persky, MD; Donald Respler, MD; Honey Shields—Beth Israel Medical Center—Singer Division, Child Life Center; Mark Sultan, MD; Tova Yellin, MD—Maple Avenue Pediatrics; Barry Zide, MD.

Special thanks to Target Therapeutics—Boston Scientific Corporation

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