

# Giving Him Wings

By Debbie Breslow

"Mommy, look at that little boy's nose!" "Ooh, that must've been quite a fall, is he o.k.?" "What's the story with the rubber nose?" "Is that elephantitis?" "Honk, Honk, are you a clown?" "Oh, my sister's kid had that. It went away by the time he was five." "Talk to your doctor, they are doing wonders with laser-in fact, my neighbor said..." I wasn't interested in what her neighbor said.

"What's wrong with his face?" said a little boy to me at the park yesterday. "Oh, it's a birthmark". I responded. "Does it hurt?" he continues. "No", I replied. "Maybe you should give him a bath tonight. And tell him to use soap!" he recommended confidently. "Thanks for the advice", I thought to myself. Then I looked down at Kenny to check his reaction to what the little boy had said. He was already planted in the sandbox, building a sandcastle with his favorite stuffed dog, Duke.

Kenny is three years old. To date, the aforementioned questions and comments really haven't seemed to faze Kenny. To

date, I try (vigilantly) not to let them faze me either. But some days are better than others. I'd like to believe that with age comes wisdom and that I'm wise enough not to let this stuff get to me. After all, isn't it human nature to notice and perhaps question someone who looks different? But it's my kid.

Kenny was born with an arteriovenous malformation (AVM) of the nasal and malar



Kenny Breslow playing the guitar

region. His lip and left cheek are red and engorged due to an over-activity of blood supply to the area and he has frequent nose bleeds. We were told at birth that it was a "bruise" resulting from birth trauma. By the time Kenny and I were discharged from the OB unit, we were told that the "bruise" was a port wine stain and that it could be removed successfully with laser surgery.

Sixteen unsuccessful laser surgeries later, we discovered that Kenny's birthmark was an AVM. We are fortunate to have established relationship with a world-renowned endovascular surgeon and remain hopeful that Kenny's condition, though incurable, will be kept under control.

The details of our clinical research, diagnostic trials and tribulations, and exhausting hospital experiences are no more difficult, unique or draining than for anyone who has a child with a medical condition that requires ongoing intervention. What remains most difficult for me, however, is my ability to remain strong, optimistic and hopeful that Kenny will have the backbone he needs to face and deal with the ignorant remarks, questions and potentially harmful teasing that are typically associated with kids who look different.

When I get bogged down with worry about Kenny's lifelong coping abilities, I am reminded of quote once read by Eleanor Roosevelt:

*"No one can make you feel inferior without your consent"*

I must recognize and accept that this is his life to lead. As his mother, I can do all I can to foster his self-esteem, provide him with love, support and encouragement, and teach him the importance of tolerance. Kenny is the one who will have to experience life with a facial difference firsthand. I know he will get through it in the best way he knows how. But he's still my kid.

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## Vascular Anomalies Conference 2000 NYU Medical Center on April 7th and 8th 2000

On April 7th and 8th, an international conference, entitled Vascular Anomalies 2000, was held at NYU Medical School with Dr. Judah Folkman, a noted researcher in the field of blood vessel growth, as the keynote speaker. The event featured guest lecturers from the Institute of Reconstructive Plastic Surgery, the NYU School of Medicine faculty and other medical centers around the country including Mayo Clinic, Boston Children's Hospital, Beth Israel Medical Center (NYC), Duke University, Colorado Neurological Institute, Children's Hospital of Los Angeles, Arkansas Children's Hospital and Lenox Hill Hospital among others.

The first day focused on an historical perspective and classification of the various anomalies, genetic advances, and imaging issues and closed with a discussion of the deleterious effects of misdiagnoses and late referrals. On Saturday morning, the conference delved into multidisciplinary management of vascular conditions beginning with a lecture on the

psychological aspects of these conditions. The lectures highlighted the multidisciplinary approach, then examined the differing opinions on surgical and non-surgical intervention. In the afternoon, talks were given on the special surgical considerations given to limbs, lips and the nose, and the effectiveness of superficial and deep laser therapy. The Conference ended with lectures on venous and lymphatic vascular malformations; a description of various therapeutic situations, the advantages of multidisciplinary vascular anomaly centers and support groups. Graphic slides were used throughout the presentations to illustrate the patients discussed, both before and after their procedures. The Institute was represented by Drs. Phillip Casson, Joseph G. McCarthy, Francine Blei, Barry Zide, Alice Pope, PhD., Seth Orlow, Robert Rosen,

Alejandro Berenstein and Nolan Karp. The conference was such a success of sharing and discussing information that another conference is scheduled for next Spring.

