

Quang Nguyen's BRIEF HOLIDAY FROM PAIN

by Annie Schwechheimer

Quang Nguyen

Quang Nguyen loves to swim. Although he also enjoys drawing, playing with LEGOS, watching Chinese Kung Fu movies and *Superman*, swimming is his favorite hobby. In the water, the legs that normally cause him so much pain are weightless, allowing him to imagine, if only briefly, what life would be like if circumstances were different. If he hadn't been born with severe hemophilia A. If he hadn't been born in a country with limited medical resources.

Ten-year-old Quang lives in Ho Chi Minh City, Vietnam, with his mother, father and 13-year-old brother Quyen. Because of Quang's hemophilia, the family must daily endure tremendous emotional, financial and physical burdens. The factor needed to treat Quang's bleeds, when available, is too expensive for the Nguyen family. Quang is unable to walk on his own, and must rely on his mother to carry him to and from school. The school Quang attends is not handicapped accessible, so he must sit in the same seat for hours, watching his friends run and play at recess.

Quang's mother Ngoc worries about him when he is at school. "As he gets older, his bleeds get [more] frequent," she explains. "That makes me worry more, but I cannot think about his future." Ngoc has even put Quang on a special diet of rice to keep his weight down. If he gains weight, she says, it will increase his chance of bleeding and he will need more factor. Right now, the biggest challenge for the Nguyen family is finding factor when a serious bleed occurs.

photos: Julia Nguyen



Humiliating conditions:

Because Quang's legs are permanently damaged, his mother must carry him everywhere—even to the bathroom at school.

Frequent bleeds:

As he gets older, Quang experiences more frequent bleeds, leaving him confined to a wheelchair and unable to do basic tasks for himself.



Thankfully, Project SHARE has been able to help Quang. We first learned about him in January 2001 when his aunt Julia, who lives in the US, contacted us on Quang's behalf. During the past three years, we have made several donations of medicine and supplies to Quang. When he was hospitalized in April 2003 with bleeding in his knees, nose, eyes and abdomen, a donation of 20,000 IUs enabled him to recover.

Although he's occasionally depressed about hemophilia and its challenges, Quang takes comfort in the knowledge that there are other children like him in the world. He is especially grateful for programs like Project SHARE. When factor from Project SHARE arrives at the Nguyen home, the family rejoices. For a brief time, their worries about providing medicine for their son are over.

To learn more about Project SHARE and how you can help patients like Quang, please visit www.kelleycom.com/iha/projshare.html or contact Director Annie Schwechheimer at (978) 352-7657 or annie@kelleycom.com.

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