

CLINICAL TRIALS

Following Directions, Following Hope

A Parent's Story **An Act of Faith and Medicine**

By Karen B.

The kids were singing along with Barney..."We're a happy family" while my husband and I locked the door to our room. We were finally ready to begin.

Lined up along the edge of the dresser were the alcohol swabs, syringe, needle and cold bottles of interferon. A pile of Tootsie Roll pops and Gummi bears sat hidden behind the lamp, waiting to rescue us in case things got tough.

The worn instruction sheet had endured our endless reviews:

First, assemble the needle and syringe.

Next, carefully mix the powder and the liquid as directed.

Fill the syringe as directed. Check for bubbles.

Inject into thigh as directed, at the angle shown in the drawing.

Pull the syringe and check for blood; if no blood, proceed to inject as directed.

As directed, as directed. I was no longer certain that I could act as directed. I didn't want to stick a needle into my 3-year-old child's chubby, perfect thighs three times a week for the next year.

We had requested this chemotherapy, not yet FDA-approved for children, in a desperate attempt to help his body attack the hepatitis virus that was damaging his liver. It was the only option doctors reluctantly offered, with no guarantees attached.

They cautiously pointed out that it was a treatment, not a cure, that he had a statistically low chance of responding. The final decision, as always, fell into our nervous, sweaty hands. Now we wiped those hands one more time, opened the door and carried our son into the room.

We remained hopeful for over seven months as he endured the injections and frequent blood draws. But eventually the interferon negatively affected his blood count and we had to stop. Ninety-six shots had failed to stop this tenacious virus. If only he had been immunized at birth—with just three shots—the virus would never have survived in his body.

If only...