

Parent Empowerment Newsletter



Crossroads

NEW three-part series examines how the changing national hemophilia landscape is impacting patients and their physicians, affecting product choices, and determining the ultimate winners in the war over factor sales.

Part 1

Patient and Physician: Communication and Conflict in a New Hemophilia Era

BY KEVIN CORREA

When a person with hemophilia finds the right hematologist and hemophilia treatment center (HTC), you might think Cupid has been busy with his quiver of arrows. *We love him, or she's a godsend, or the staff is like family*, are all common accolades. But for the hemophilic patient who fails to make this happy connection, working with the HTC system can be fraught with stress and tension. And even when personalities mesh, the hemophilia industry itself may unravel the relationship.

With HTCs and home care companies competing for factor sales, physicians vying for research dollars, and insurance companies entering the specialty pharmacy arena, big business and medicine are colliding. Unfortunately, the hemophilia community is caught in the middle. A lot of money is at stake,

and many patients are getting lost in the mix.

It's up to the patient to make sense of the ever-changing hemophilia landscape. Now more than ever, patients and families have a wealth of knowledge at their fingertips. Thanks to the Internet, we have information we only dreamed of twenty years ago. Today, patients can be better equipped to successfully navigate the turbulent waters of the hemophilia industry.

From Knowledge to Empowerment

Dr. Joe Walker,* a hematologist at a metropolitan hospital, stresses that good communication is the centerpiece of a successful patient-physician relationship. "To be effective, communication has to take place as a dialogue, not simply doctor dictating and patient listening," he says. "As doctors, we need to appreciate that each patient and family is unique, and we must engage in dialogue within that context."

continued on page 10

* Names of patients, parents and physicians have been changed for anonymity.

inside PEN

- 3 As I See It: The Missing Piece of the Puzzle
- 4 Inhibitor Insights: CommUNiCation: You and I
- 5 Storm Watch: A New Law, A Mother's Dream
- 6 Transitions: There's a New Chef in Town
- 7 Homefront: Dripping on the Independence Dance
- 8 Richard's Review: Remembering Dr. Charles Drew