

The Times Herald

Norristown, and Montgomery County, PA

NORRISTOWN — In an effort to spur awareness of a health care problem affecting many who suffer from immune deficiencies, a doctor and his patient recently came to The Times Herald newsroom to shed light on some issues.

The question Dr. R. Michael Blaese wants answered — should a patient’s safety be put at risk as a result of a business decision?

That could be the case with Adam Brock, originally from Hershey, a 16-year old battling common variable immune deficiency (CVID) since he was six months old. CVID is a type of primary immunodeficiency disease (PIDD), which means Brock’s immune system does not produce the antibodies it needs to fight off infection.

Brock receives monthly intravenous therapy, which helps replace the antitoxins his body fails to naturally produce. He has spent 16 years experimenting with different medications and is finally stabilized on one. Now, his family’s medical insurer had changed its policy to require all its patients to switch therapies to one which is preferred by the insurance company.

Brock’s mother, Colleen, a registered nurse and mother of two children afflicted with PIDD, said she has seen it all — from when her son was born, the complications started almost immediately. Brock was gravely ill throughout much of his early life and was put on medications to stabilize his health. He would have adverse reactions to different medications. His blood pressure would plummet, his heart rate would drop and his temperature would skyrocket.

Blaese is an immunologist and medical director for the Immune Deficiency Foundation (IDF), a national nonprofit patient advocacy organization, based out of Towson, Md. He said Brock’s health could be in major jeopardy if his insurer, Health America, an offshoot of Coventry Health Care, forces him to switch from a medication he is already stabilized on, to a generic brand approved by the company.

“Usually, patients require lifelong therapy,” said Blaese.

“We discovered the leading cause of reactions is switching from one product to another. About 35 percent of all reactions are caused by that context. You’re saving relatively small amounts (of money) and you’re putting patients at great risk. By mandating that every patient start this other product that they’ve never had before, you know that you’re going to have reactions. It’s inevitable.”

Brock’s mother said she has been through the ringer.

“On Adam’s first Christmas, we planned his funeral,” she said.

“To go from that, to this, I will fight tooth and nail to keep him healthy. That’s my job.”

Brock's treatments cost a whopping \$3,500 every three weeks, something Colleen Brock is grateful is covered under their insurance.

From aches and pains to strokes and anaphylactic shock, any number of medical reactions can afflict PIDD patients who swap one medication for another. Blaese said there are about 10 products licensed in the U.S. to treat PIDD, and none is a cure-all.

"We can't predict who's going to get a reaction and we can't predict how serious that reaction is going to be," he said.

"It all has to be efficacious in preventing infection. They're all manufactured differently. They all have to have separate clinical trials to prove that it works. For the individual patient, this is not a generic drug. This is a very specific one. Once you get stabilized on one drug, chances are you will be able to tolerate it for a decade or longer. But once you switch, you're putting yourself in harm's way. There's just no medical justification for that. It's strictly an economic one from the point of view from the insurance companies, so they can negotiate with one manufacturer or another."

Coventry Health Care is the nationwide umbrella company that owns Health America, which offers a number of different health plans for people. Blaese contends the company's list of preferred drugs eliminates the role physicians have in prescribing intravenous therapies for patients.

Matthew D. Eyles, vice president for public affairs and policy at Coventry, said the company's goal is to provide quality care to members who rely on such therapies.

"It has not been uncommon for patients to change immunoglobulin (IG) treatments, and there is no evidence in the peer-reviewed medical literature to conclude that patients who move from one IG product to another have a higher incidence of problems," he said.

"However, recognizing that each member's situation is unique, we have numerous medical criteria that allow physicians and members to work with us to stay on their current treatment or receive coverage for an alternative therapy."

But doctors in neighboring fields have echoed Blaese's sentiments.

"Changing patients stabilized on a particular product is irrational, since the process of changing is cumbersome and not all patients tolerate all products. Some will only tolerate a few, or even one," said Dr. Jordan Orange, a pediatrician specializing in immunology and allergies with the Children's Hospital of Philadelphia (CHOP).

"The danger is lumping a group of patients together into one — this is a very individual disease," said Colleen Brock.

"I have two children, they are very different. My daughter gets very sick in the summertime, with pneumonia, eye infections, ear infections. Adam gets very, very sick in the wintertime. They are very different in how their immune systems react to things. Patients are not the same. It can't be one medication

that treats everybody.”

Adam Brock sees an immunologist, a pediatrician, a gastroenterologist, a cardiologist, a neurologist and has undergone brain surgery twice in the last 11 months.

Blaese stressed the complexity of each patient’s PIDD, that 150 diseases are simply caused by genetic misspellings. Some appear in infants while others occur upon adulthood. He was reminded of the story of the boy in the plastic bubble, forced to live in a microbiologically sterile environment.

“Once you get the treatment, you learn to deal with it,” said Adam Brock.

“It’s better than being out of school all the time. Once you know what you have, its easy to figure out the solution and deal with the problem, but you have to keep dealing with it.”