

Lifetimes

SPRING 2002

Virginia Birth-Related Neurological Injury Compensation Program

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“Her Daddy’s Right There”

Janis and Larry Swanson’s daughter Amanda was accepted into the Virginia Birth Injury Fund Program four years ago. “The Fund is the best thing that has happened to Amanda,” said Larry. Janis works for Ryan Homes, and Larry builds custom homes and is involved in real estate and land acquisition. They live with Amanda and their six-month-old daughter, Hayley, in Centreville, Virginia. Larry graciously agreed to share his family’s story and experience with the Birth Injury Fund.

“We do what we have to do. We take care of Amanda. She’s our daughter—that’s the way it is,” explained Larry, an involved father who perceives problems as opportunities: “You’ve got a choice: You can deal with it or let it cave you in. I prefer to deal with it.”

“Amanda is so bright and engaging,” said Larry. “She says so much with her eyes. The

way she responds to her mother and me—it’s amazing. I can walk into a room, and her eyes will follow me wherever I go. I walk in, and it’s, ‘Oh, Dah.’ She gives me a smile that would light up the universe.”

At four feet, eight inches tall, and eighty-five pounds, Amanda has hazel eyes and chestnut brown hair, long and flowing. She will be eleven years old on July 10.

Larry explained that communication is difficult for Amanda, who is almost completely non-verbal: “I think it is a lot of Amanda’s frustration. We’re working right now on her communicative ability.”

Amanda loves attending school at Kilmer Center in Fairfax County, where she is learning to use an adaptive speech device called the Dynavox 3100. It was



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recommended by Amanda's revered teacher, Betsy Calvert. "She's made such a difference in Amanda's life," said Larry. "When I think that things are really bad, and I look at Amanda and start to worry about her future, I go to her

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excellent school and see how much better and more responsive she is—that gives me strength and encouragement."

Along with her lack of expressive language, Amanda has limited fine motor control and is non-ambulatory. Larry explained that, with a spastic quadriplegic with dystonia, "It's an all-or-nothing thing. Either she's very stiff or very loose. She doesn't have a middle ground." A Baclofen pump was installed a couple of years ago to administer the muscle-relaxing drug.

This past Labor Day, Amanda experienced health problems that were difficult to diagnose. Symptoms included spells of thrashing and fever spikes. She was hospitalized seven or eight times for a total of three months during a six-month period.

It was finally determined that the catheter connection was cracked. Certain movements caused the Baclofen to dump out of her catheter, putting Amanda into Baclofen withdrawal, which Larry compared to the agony of heroin withdrawal.

"We've since had to have the same thing repaired twice, but we think we've made all the necessary modifications to avoid this happening again."

Larry works a flexible part-time schedule to accommodate Amanda's repeated hospitalizations:

"When Amanda's sick I stay by her side 24/7. Every time she's in the hospital, her daddy's right there." Larry and Janis handled the difficulty of simultaneously tending to Amanda's illness and Hayley's birth. Amanda was hospitalized a week

before Hayley was born and again five days after they had brought Hayley home.

Larry noted that his dedication to his daughter's caretaking may not be the norm. Because he perceives men as responding differently than women to such an emotional challenge, he believes men face different issues in raising a handicapped child.

"Men look upon things as always trying to establish order," said

Larry. "Men want to take a problem and fix it. This is a problem that has no fix. This is a problem that's lifelong. Typically, women would probably deal with it better, because it's more a



matter of nature and nurture.” And is Larry’s approach any different? “No,” he admitted, “I’m still trying to fix Amanda’s situation every day.”

According to Larry, enrolling in the Fund was “the smartest thing I ever did for my daughter.” The Fund gives him enormous peace of mind, “knowing that my little girl will always be safe and that my family will not be destroyed by catastrophic medical bills.” The Fund has already expended hundreds of thousands of dollars—over \$110,000 last year alone—for Amanda’s care, including her medical treatment, her feeding, a specialized van and modifications to the custom house Janis and Larry built in 1995, before Amanda was admitted into the Fund.

They designed their home to accommodate Amanda’s special needs. Larry explained, “We recognize that, in the world today, Amanda’s going to have a lot of doors closed to her. We wanted to make certain that home was not a place where that was the case.” Donna Jeffries, who lives at their



home, helps with Amanda’s caretaking. “We have a very special relationship with Donna,” said Larry. “She’s a part of the family.

“We’re just parents who love our children,” said Larry. “We make the adjustments to our lives to accommodate what our daughters need.” Although Amanda was initially reluctant to accept Hayley “because she’s stealing her thunder, basically,” the sisters’ relationship has been better since Amanda’s health has improved: “I don’t think we’re going to have an issue.

“Amanda’s very intelligent. She understands everything we say. But she’s chained within a body that won’t let her do things; she can’t communicate the way she wants to. We try to offset it with love, understanding and attention. It’s going to require a long time to work through. She’s coming along. It’s just a long road.

“We don’t know what Amanda’s future may hold. We always have hope for Amanda—we’re so proud of her. If we can break through enough barriers, she’s going to do something. I don’t know what. It doesn’t have to be big—it just has to be something that makes her happy. That’s all we care about.”

REMINDER:

Send in healthcare information!

Families, please send in copies of your insurance cards and healthcare plans to Lynn Cuozzo, Insurance Manager.

REMINDER:

There is a message board for families on the Web. Family members are invited to sign into the message board at our Website at

www.vabirthinjury.com.

Families can share their experiences and information on such topics as the types of medication proving effective for their children, therapies they are trying, and ways to ease recovery time following surgery.

Fund Welcomes New Executive Director

The Virginia Birth Injury Fund Program is pleased to announce that George T. Deebo has joined us as our new executive director.

“I’m delighted to be working with the Birth Injury Program and look forward to meeting everyone involved,” said Deebo. “It’s exciting to have a role in a program that’s vital to those receiving assistance and to the participating physicians and hospitals.”

Recipient of the 2001 Virginia Primary Care Association’s Special Recognition Award, Deebo brings to the Virginia Birth Injury Fund Program extensive nonprofit management experience. Deputy Director of the Virginia Primary Care Association, Inc., in Richmond, for the past nine years, Deebo was formerly Communications Specialist with (Trigon) Blue Cross Blue Shield of Virginia and Communications Manager for the Christian Broadcasting Network.

Deebo earned his undergraduate degree from Davis & Elkins College, Elkins, West Virginia, and his master’s degree from Regent University, Virginia Beach. He also received a Certificate in Management of Volunteer Programs from Norwich University, Vermont.

Sharon Payne, who served as acting director in the interim, will continue in her



GEORGE T. DEEBO

position as assistant director. She said, “I’ve learned an immense amount as acting director in the last few months. Although I’ve enjoyed it—I especially enjoyed talking to and meeting the families—I join everyone here at the Birth Injury Program in extending a warm welcome to George Deebo as our new executive director.”

Farewell to Elinor Pyles

The Virginia Birth Injury Fund bids a fond farewell to Elinor Pyles, executive director of the program since 1987.

“Elinor Pyles has been the only director since the program started,” said Sharon Payne, assistant director. “She’s done a wonderful job, bringing the program to where it is today. At the beginning of the program, in the first couple of years, we probably had five or six children. Now we have over sixty children in the program. The evolution of the program has really been her doing.”

Payne marveled at Pyles’ dedication: “She’s worked weekends, ten-hour days, holidays, just has put in a lot of personal time for the children of the program. She is so dedicated to the children. It’s never been any other reason except that she feels very strongly towards these children.”

In recognition of Elinor Pyles’ inspired leadership and dedicated service, everyone at the Virginia Birth Injury Fund expresses great appreciation for her efforts on behalf of the children. We wish her all the best.

U P D A T E S

Fund Welcomes Case Manager

Terri Starr has joined the Virginia Birth Injury Fund Program as case manager, a newly created position. She will be working directly with all the families and conducting in-home visits.

JLARC Audit

The Virginia Birth Injury Fund is currently being studied by the Joint Legislative Audit and Review Commission of the Virginia General Assembly (JLARC). The comprehensive study will examine administrative issues, funding procedures, the role of the board of directors, and ways to improve the program. The final report will be completed by the end of 2002.

C A L E N D A R

April 23 — Exhibit at Perinatal Conference at Wyndham Roanoke Airport hotel.

May 9 — Speaking engagement at May meeting of the Virginia Chapter of the American Society for Healthcare Risk Management at The Jefferson Hotel in Richmond, Virginia.

July 26-28 — Exhibit at the Virginia Chapter, American Academy of Pediatrics annual meeting.

The Program Defined

The Virginia Birth-Related Neurological Injury Compensation Program helps take care of babies born with serious birth-related neurological injuries. It is an exclusive, no-fault remedy that is both quick and confidential. The program provides compensation and covers expenses insurance and other programs don't, not just through infancy and childhood, but for life.

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Birth Injury Fund Staff (left to right) – Terri Starr, Sharon Payne, Lynn Cuozzo, George Deebo, Dan Liberty and Robin Lucas.

CURRENT STATUS

62 Children

Currently receiving compensation

493 Physicians

Participating in 2002

27 Hospitals

Participating in 2002

112 Claims

Have been filed since the Program began, of which 7 are pending

\$5,984,783

Claimant expenses in 2000

Virginia Birth-Related Neurological Injury Compensation Fund

STAFF

George Deebo
Executive Director

Sharon Payne
Assistant Director

Dan Liberty
Accounting Manager

Robin Lucas
Accounts Payable

Terri Starr
Case Manager

Lynn Cuozzo
Insurance Manager

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