

# New Horizons

Housing That Supports Independence



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## ***Our 19th Golf Classic on May 24th In Pictures***

Project Freedom held its 19th Annual Golf Outing last month with over 100 golfers participating.

The Outing was held at Cobblestone Creek Country Club in Lawrenceville, and was sponsored by:



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Funds raised by this event go toward our recreation and support programs for the tenants such as the Organic Fresh Food distribution program, and shore trips,

***Project Freedom, Inc. wishes to thank our sponsors and benefactors who have provided valuable support to our organization throughout the year.***

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# “My Two Cents”

By Tim Doherty, Executive Director



***“Happy Trails to you, until we meet again, Happy Trails to you, keep smilin’ until then. Who cares about the clouds when we’re together? Just sing a song and bring the sunny weather. Happy Trails to you, till we meet again.”***

Such were the words to the theme song to the TV show, “Roy Rodgers and Dale Evans” back in the 1950’s. And they fit for my last article in our Newsletter, as Project Freedom’s Executive Director. As of July 1, 2021 I will be retiring as ED, giving the reigns over to our own Tracee Battis. Knowing Tracee as I do, I am confident she will do an outstanding job, and provide great leadership into the future. And of course, Norman remains our founder, who constantly reminds us of his vision and mission—Independence. His influence will continue on and into the future.

I must say, that I never had any idea, that this would be the last place for me to end my career. Back in 1997, I had stopped to talk with Norman about selling my accessible van, thinking that it would be better to sell to someone who really needed it, rather than just trading it in. Our conversation that day led to my giving a presentation to the Board of Trustees, who offered me the job. And as they say, the rest is history.

However, my history with the community who are disabled, really started back in 1974, when my daughter, Jennifer was born with CP. Back then there weren’t many options for services let alone housing. Marion and I would be involved in organizing parent support for educational opportunities, and ultimately I became involved with Norman in forming Project Freedom. I remember Norman coming into my gas station with his Dad, and talking to me about his ideas and his vision for independence. I joined the Board, and became the first Chairman of the Board of Trustees. As a volunteer, we lobbied our public officials to get funds to build our first housing community in Robbinsville, called Freedom I, which opened in 1991. Fast Forward to today, and ten projects later, we are just completing our Robbinsville Town Center project, and about to break ground on our second one in Hamilton Township, across from the Library.

I must say it has been a lot of work, not always enjoyable, but always exciting. Finding a suitable site, getting town approvals, getting our funding, managing the construction, doing the lease up and hiring staff—all things that can lead you to pull your hair out. But in the end, very worthwhile.

So, as I sadly write these words, I don’t have any regrets whatsoever. I have been fortunate to have worked with our great staff, which keeps growing every day. With our consumers, who I know treasure our housing because it makes life easier and gives them a safe, and clean environment. I’ve also enjoyed working together with my wife Marion, for the past nine years, in a professional capacity, and really need to share my success with her. And of course our Board of Trustees, who for the most part, took on the enormous risks involved, and supported our housing developments.

So, one thing Marion and I have always done, and that is follow the Holy Spirit and trust in the Lord. God Bless, keep well and “Happy Trails to you, until we meet again”.





## ***From Norman's Desk***



For most of my life and well into adulthood, June represented the end of school and the beginning of the Summer season. Even after leaving college too many years ago, June felt like the end of a period of intense work.

More recently, as my readers are keenly aware, June became my month to remind everyone to be prepared for Hurricane Season, which “officially” began on May 15.

Much more recently, June has been the month to write about being a father. I have only celebrated Fathers' Day 13 times as a father. Celebrating the day as a father is far different than celebrating as a son with my father. For one thing, a son is trying to show his Dad his love and appreciation that he feels for him while the Dad wants to show his son (or daughter) the wonderment and pride of being Dad. Being Dad to any child is wonderful and awesome. Father's Day is the icing on the proverbial cake.

Fatherhood and Motherhood can be daunting and pleasurable at the same time. Every parent knows this mixture of feelings. I think, however, those of us with obvious disabilities also feel an additional mixture of emotions. Indeed, there is pride of your child and pride of being a parent when others think you should not or cannot be a parent.

There is also the apprehension of being judged by others because you have a child and a disability. Your capabilities and skills as a parent are constantly being scrutinized to see if, indeed, you can take care of your child. This scrutiny is always in the back of your mind as you try to let your child experience what other children experience.

This is the unfortunate price we pay by being parents with disabilities. Years ago the White House sponsored a conference on parenting with disabilities because more people with disabilities are paying that price nationally. The price can be minimal for some, higher for others, but well worth it to hear your son say “Happy Fathers' Day, Dad!”

Norman A. Smith, Co-Founder/Associate Executive Director  
Follow us on Twitter @TheFreedomGuys  
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## ***Teen's Documentary About Life With Disabilities To Screen Worldwide***

*Reprinted from The Baltimore Sun/TNS | May 18, 2021 by John-John Williams IV*

BALTIMORE — Faith Guilbault does not want pity. She just wants friendship.

The 17-year-old from Bel Air has not let cerebral palsy stop her from being a featured model during New York Fashion Week. It has not prevented her from regularly riding horses, playing sled hockey or even skydiving. The cheerful go-getter will allow the world to get to know more about the realities of her daily life with disabilities through a documentary, "Faith's World," which she directed.

The 27-minute documentary, which premiered in April on Maryland Public Television, eventually will be sent to 1.8 million American teachers in 155 cities this spring. It will then be shown in 150 countries across the world. The film, with an introduction by actress Ashley Judd, comes with a teaching toolkit.

"It makes me feel really good. It makes me feel that I'm doing something that is going to be worth so much to people," said Guilbault, who attends the Maryland School for the Blind where she is a junior. "I thought it would be an inspirational film. I wanted to put awareness out there."

Holly Carter, founder and executive director of BYkids, a New York City-based nonprofit that produced the documentary, believes that audiences will fall in love with the Guilbaults. "Faith is open, joyful, reflective, generous and comes with the most amazing family," Carter said. "We got her mom, dad and even brother in the film. This is an incredible, strong, optimistic family."

The past 13 documentaries from Carter's company have included topics ranging from race to climate change. "I think the intent is the humanization of hard topics so that people can talk about it to help American young people think about these large topics," Carter said. "Because it is personable, it can become actionable."

An estimated 61 million people in the United States live with a disability, according to the Centers for Disease Control and Prevention. "One out of six Americans deals with disabilities," Carter explained. "It's a huge group. My job was trying to humanize them."

Carter discovered Guilbault when she was modeling at a fashion show in New York. She was struck immediately by the teen's energy, fearlessness and willingness to try new things. "Faith's resilience shines through. When we picked Faith the day before the Runway of Dreams Fashion Show (an annual show featuring models with disabilities), we didn't know she was doing skydiving and horseback riding. She's an adventurer," Carter said.

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The documentary was shot over the course of a month in 2019 and includes scenes from New York City for fashion week and then at the Guilbault family's Bel Air home.

Guilbault's mother, Karen, said that she is excited to see how many people her daughter will "touch." She added: "There are things she has to work twice as hard to do. She doesn't let anything stop her."

Depending on how far she needs to travel, Guilbault will use either a walker, wheelchair stander or house cane. In addition to cerebral palsy, she also has epilepsy and cortical visual impairment, a condition where vision is decreased due to a neurological problem affecting the visual part of the brain.

What's next for Guilbault? She wants to get a service dog and live on her own by the age of 22. She also wants to star in a reality show, be an author and work in a day care. But most of all she wants to continue to educate others "and to let people know that people are different and that's OK. I want to put awareness out there."

## ***Should Nurses Take a 30% Pay Cut When Their Patient Turns 23?***

*Reprinted from an article in the New York Times By John Florio and Ouisie Shapiro / Published April 30, 2021 Updated May 1, 2021*

With one ear on the sound monitor linked to his daughter's room, Joe Trimarchi sat at his dining room table in the Rosebank section of Staten Island. He was stuffing dozens of envelopes, hoping that one of them would land on the desk of a politician who might care. Mr. Trimarchi, 55, is a cashier in the billing department of Staten Island University Hospital, but what animates him is advocating for his daughter Alexia.

Since she was born 20 years ago with spastic quadriplegic cerebral palsy, a seizure disorder, and hydrocephalus, he has been pestering government agencies and state senators. The Trimarchis have endured two decades of anxiety, hospitalizations and middle-of-the-night scares. But now, the family is facing a full-blown crisis. When Alexia turns 23, the New York State Department of Health will change her classification from "medically fragile child" to "medically fragile adult." That distinction, which may seem minor, has enormous consequences. For one thing, Alexia's caregivers will no longer receive the same hourly rate to which they've become accustomed.

Alexia is one of around 1,500 medically fragile children in New York State who depend on Medicaid for private-duty nurses. Children deemed medically fragile require continuous nursing care as well as life-sustaining medications and treatments. In addition, many rely on interventions like feeding tubes, ventilators or supplemental oxygen.

None of them can afford to lose their caregivers. But for the nurses, the situation is untenable: When medically fragile children are deemed adults at age 23, the nurses who care for them lose roughly 30 percent of their pay.

Aziza Hankins, a licensed practical nurse, has been with Alexia since she was a little girl. But in three years, when Alexia is considered an adult, Ms. Hankins's rate will drop to \$23 an hour from \$32 an hour, and she fears she'll have no choice but to leave for a higher-paying job. "As much as I love Alexia," Ms. Hankins said, "I'm not going to be able to continue with her. It's completely unfair, but I have a family to care for, too."

Medicaid rates for private-duty nursing had been stagnant for more than a decade. Then, in a move many in the industry had spent years agitating for, the Department of Health granted nurses who care for medically fragile children a series of three raises, the second of which went into effect in April. The state also tacked on a 30 percent bump in pay, what it calls an "enhancement." But all of these financial benefits roll off the table when patients reach adulthood.

Already, private-duty nurses like Ms. Hankins make far less than they would in hospitals, where nurses with comparable skills earn close to a six-figure salary, in addition to health benefits, vacation pay and sick days. As independent contractors, private-duty nurses do not receive benefits. But those who pursue the specialty often do so because they prefer to work with individual patients and want the flexibility of choosing their own assignments. Still, Ms. Hankins struggles with her decision. All those years spent with Alexia have resulted in a close bond between the two. Alexia is unable to speak, but she and Ms. Hankins have developed their own way of communicating.

According to Margaret Mikol, the executive director of SKIP of New York, an advocacy and service agency that helps families navigate the home health care system, the hourly rate for private-duty nurses shouldn't go down when a patient gets older; it should go up. "The care doesn't stop," she said. "If anything, the older someone gets, the more difficult they are to take care of. Who's harder to lift? Who's harder to move?"

The Department of Health has already raised the age cap once. When asked if it had any plans to remove the cap altogether, the department emailed a response to The Times: "Funding was specific to medically fragile children, which previously only covered people to age 21; however, in October 2020, the age was increased to 23."

Jonah Bruno, director of communications for the Department of Health, added: "We support all efforts to ensure that the most vulnerable New Yorkers receive appropriate care and to ensure their caregivers are compensated fairly." In addition to raising the age of eligibility to 23, he added that the department "is following through with a \$26 million investment this fiscal year on private-duty nursing services that's projected to nearly double to \$51.4 million next fiscal year. No additional changes are being contemplated at this time." That disbursement, Ms. Mikol said, was welcome, but she was perplexed that the money did not extend to medically fragile adults.

There was also some hope that the recent federal stimulus would enable the Health Department to lift the age cap. But although the money restored many cuts to programs for those with developmental disabilities, the nurses were left out, Ms. Mikol said. “We haven’t seen a penny,” she added.

“I was always writing letters and stuff,” Trimarchi said recently. “But the last few years, I started inviting politicians over to the house. Because when you see with your own eyes, it’s better. People don’t understand unless they live it.”

State Senator Diane Savino, a Democrat who represents parts of Brooklyn and Staten Island, was one of those who took Mr. Trimarchi up on his offer. After visiting the Trimarchi home, she weighed the issue, spoke with nursing agencies and came away strongly in favor of eliminating the age cap altogether.

The New York State Office for People with Developmental Disabilities serves 120,000 New Yorkers, 38,000 of whom live in group home settings. But according to Mr. DeGrottole, of Community Resources Staten Island, more than a decade of budget cuts has crippled the industry. Group homes are shrinking, merging or on the verge of closing altogether. “People in the industry fear that New York State’s agenda is to reduce the amount of certified beds,” Mr. DeGrottole said.

Keeping the medically fragile at home is a relatively new concept. Until the 1980s, most people with severe developmental disabilities were placed in hospitals or large institutions. But hospital care was expensive, and the institutions notoriously neglected their residents. By then, New York had begun turning away from institutions in favor of smaller group homes, and more recently it has bolstered in-home care. The financial advantages of keeping those who are medically fragile at home are undeniable. According to Community Resources Staten Island, a nonprofit provider of residential programs, it costs New York State \$135,000 to \$156,000 per year for a medically fragile child to be in a group home, as opposed to an average of \$69,000 for in-home care.

So why the change in nursing-rate reimbursements when a patient reaches his or her 23rd birthday? Given the numbers, why doesn’t the Department of Health encourage in-home care?

Michael DeGrottole, the chief operating officer at Community Resources, offered his opinion. “They just never thought these kids would live into their late 20s, let alone their 30s,” he said. “Now they’re living into their 50s and beyond.”

Mr. Trimarchi plans to lobby all 63 New York State senators, pleading for them to lift the age cap, to allow his daughter to stay at home. And so, in the coming months, he’ll be spending his evenings at the dining room table, a stack of papers and envelopes by his side.

## ***Customers Bank Donates \$5000***



Pictured from left to right are Randy Hanks, Deb Runyon, Tim Doherty, Norman Smith and Steve Schaefer



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**Project Freedom Inc. is a 501 (c)(3 ) not for profit organization dedicated to developing, supporting  
and advocating opportunities for independent living for people with disabilities**

**Hamilton Fireworks and  
concert will be held on  
Friday, July 2nd, with a  
rain date of Sat, July 3rd, at  
Veterans Park.**

**If you're planning to  
attend, use the Kuser  
Road entrance to the park.**

