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Leading Advocate Susan Tatelli

*Honored for Helping People
with Food Allergies*



Best Version Media

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An exclusive magazine serving the residents of Highland Park

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Dear Residents,

I hope all the moms had a beautiful Mother's Day. Now it's time for us dads to enjoy our day in the sun. Happy Father's Day to all. This is such a busy time of year, it's hard to cover it all, but we'll try our best. Paul will tell you about Susan Tatelli in his letter and feature article. She is an amazing young lady who is making a big difference for people with food allergies. Ravinia is open again and what wonderful new amenities they have for us this year! We attended the opening of their brand new Dining Pavilion, it is fantastic and wow, the food is sooo good! Nic + Zoe 647 Central Ave., a new East Coast women's clothing store had their official grand opening as well. Please stop in and say hello. The Park District hosted their 3rd annual Champions Banquet, honoring the coaches and folks who make it all happen. It was great to re-connect with my friends Ozzie Guillen and his son Ozzie Jr., the speaker of the evening. A wonderful time was had by all and much needed funding was raised for their great cause. We'll have complete coverage in next month's issue. We do have lots of pictures this month from several events, including the 1st annual Pup Strut, Art Center and HP Legal Aid Clinic galas and much more. This month's "Chief's Brief" congratulates the 2 deserving firemen Kevin Knoll and Frank Nardomario for their promotions in the department. We love to honor those who serve us so earnestly! God bless you both. Finally, the PGA Senior Open comes to Exmore CC on July 10. Some of golf's greats will be roaming around town in the very near future. Please keep your stories and ideas coming. You make HPN great!

Enjoy The Fireworks,

Mike Stark
 Publisher

Hello Friends,

This month's resident feature is a must-read. Not only is Susan Tatelli a person you should know, her work to inform and educate people on the ever-increasing problem of food allergies has helped thousands and brought her significant recognition locally and nationally. If you're not up to speed on food allergies, you need to be, especially if you have children or grandchildren. Even if you don't read the article, please watch Susan's videos, the URL's are in her article. You'll be glad you did. I would also like to thank the great folks at North Shore Highland Park Hospital, especially the marvelous Emergency Department staff that welcomed us into their facility with all of our equipment to take pictures, even though they didn't have to, and Colette Urban of NorthShore University HealthSystem for setting everything up. We appreciate it. My wife Felicité and I also enjoyed the Hard Hat Media Event at Ravinia. We covered the new construction, restaurants and food options in our last issue, but experiencing it was a real treat. The highlight of the evening for us though was being seated at the dinner with Rob and Nancy Rotering. You won't meet nicer people.

Brgds,

Paul Clements
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Susan Advocates for Epinephrine Readiness to Save Lives

There is Nothing Susan Tatelli Can't Do

The Highland Park High School Sophomore & Recipient of the Girl Scouts of the USA Gold Award Combines Smarts, Savvy and Strength in her Fight Against Food Allergies

By Paul Clements | Photos by Scott McDougall Photography & Lynn Renee Photography

“Among food allergies, peanut allergy is one of the most severe: A minuscule amount of peanut protein may lead to anaphylactic shock and even death. Surveys show an upswing in incidence in the United States over the past two decades; a study last year estimated that nearly 2.5 percent of U.S. children may be allergic.” *Washington Post* 5/16/18

When a child is diagnosed with a peanut allergy the doctor will tell you in medical terminology that it is due to a Type 1 hypersensitivity reaction of the immune system. There are two forms of allergy testing, a skin test and a blood test. In the case of Highland Park's Susan Tatelli, when she was only 3 years old, she was given a type of blood test called a RAST test. A RAST test is used to see if an individual's blood contains an-

tibodies for a specific substance, such as peanuts. The presence of these antibodies indicates that a person is allergic.

The RAST test has a 0-6 rating scale to indicate antibody levels from 0 to 100, so a zero rating indicates a level of 0-0.35 and means you're not allergic, a three indicates a level of 3.50-17.49 and means you're highly allergic and that you have a potentially life-threatening allergy, and a six means you're basically off the charts, because you're over 100 and any exposure poses extreme danger. Susan was a 5 with antibody levels at 79.00, and that was the highest result her pediatrician had ever seen. The following year, Susan's RAST level to peanut was a 6 and by the time she was 11 they may as well have made a new chart for her because her antibody level was all the way up to 360. If you were a parent, how would you process that information? If



*Susan with her Parents Paul & Caryn Outside the April Highland Park City Council Meeting
Where She was Recognized for Her Achievements*

you got that diagnosis personally, how would you live your life knowing there is no cure?

Most of us would likely go on the defensive, protecting ourselves against exposure and carrying an EpiPen to protect against a worst-case scenario. Fortunately for us, Susan Tatelli and her parents, Caryn and Paul, chose to do the opposite, attacking the problem head-on with courage and determination.

Caryn's quest for answers began when Susan ingested a single plain orange M&M at the age of 13 months. Perhaps because of the low incidence rate and lack of awareness in the early 2000's, Susan's initial pediatrician did not test her for allergies. However, after a doctor change and an allergist referral, in addition to her peanut allergy diagnosis, it was also determined that Susan was allergic to all tree nuts. Later, at the age of 5 and after a series of unexplained anaphylactic reactions, she was diagnosed with an allergy to soy and to hemp after a separate anaphylactic reaction.

Soy can be especially difficult, because soy lecithin is an ingredient found in most food products. It serves as a preservative, but more importantly, as an emulsifier, which means it allows oil and water to mix, so it's found in everything from mayonnaise to chocolate, and from granola bars to flavored tea bags.

Most of the food allergy struggles families deal with are anything but easy and are only somewhat solved by complete avoidance and abstinence. "Actually, the soy allergy -- in our vegetarian, peanut/tree nut free household, was VERY hard," said Caryn. "Prior to Susan's diagnosis, a staple meal had been either black bean burgers, which have soy protein, or soy dogs. Plus, Edamame, which is 100% soy, had been a favorite food in our house, because it is a great source of plant-based protein."

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Susan Now in Control of Her Allergy

To put into context the seriousness of this problem, according to the Centers for Disease Control:

- The prevalence of food allergy in U.S. children increased by 50% between 1997 and 2011
- Between 1997 and 2008 the prevalence of peanut or tree-nut allergy in U.S. children has appeared to triple
- About 40 percent of children with food allergies have experienced a severe allergic reaction such as anaphylaxis, the symptoms of which are an itchy rash, shortness of breath, light headedness, vomiting and low blood pressure, and can result in death
- Every three minutes a food allergy reaction in the U.S. sends someone to the Emergency Room

The No Nuts Moms Group has a website that sadly lists the obituaries of children and adults that have died each year as a result of a food allergy reaction. Elijah Silvera, 3 years old from New York City and allergic to dairy products, died in November 2017 after being served a grilled cheese sandwich at his pre-school. Anthony Lyson, a teenager from Sparks, NV, died in July 2017 after consuming half a Power Bar that he failed to read the ingredients on. He was preparing to start college in the fall and had planned to study aeronautical engineering. Nissan Hayuni, 32 from Israel was flying to Miami with his new bride on their honeymoon when he died onboard the plane after consuming his pre-ordered kosher meal. These tragedies are sparking legislative discussions across the country from required training for daycare workers to required Epinephrine onboard commercial flights.



Susan Accepts the Gold Award from Girl Scouts of the USA

The Tatellis can relate to this. When Susan was 4 on a flight bound from Orlando to Chicago, she went into an anaphylactic reaction likely caused by airborne peanut particles. They had an emergency landing, returning to Orlando, where Susan received emergency care from EMT's on the runway. "That experience was when we realized that she could potentially die without actually consuming her allergen," said Caryn. "Terrifying."

All of these terrible things should be a call to action to everyone and this is where Susan really comes in. Her YouTube videos, "This Is What I Know" at <http://bit.ly/2pgzziU> and "How to Stay Alive (In Three Seconds) Take Two" at <http://bit.ly/2ABcAQn> have surpassed 70,000 views. These videos serve as a call to action for all people, especially teens and kids. Susan has carried her message to schoolchildren, Boy and Girl Scouts, educators and religious leaders and teachers throughout the North Shore (and beyond).

The feedback she has received on these videos has been amazing. Teachers are using them in their classes, pediatric allergists are showing them to their patients and the shares across social media have made them viral. "I believe food allergy awareness and Epinephrine Readiness saves lives, which is why I am sharing my story," Susan said, "and because teens are so susceptible to at-risk and potentially life-threatening behaviors, I want to show them that I can self-administer the EpiPen, so they can too. I also want them to always carry two epinephrine auto-injectors, because no one plans to have an anaphylactic reaction."

At the outset of her diagnosis, avoidance was the only option. "For as long as I could remember, I just wanted to be like everyone else," Susan said. "But because of the severity of my condition and the fact that I had shown I could have an anaphylactic reaction without even ingesting peanuts, I couldn't lead a normal life, or do normal kid things, like eat birthday cake, or go on sleepovers. Because of my food allergies, I grew up fast."

Susan eventually enrolled in a Phase 1 clinical trial called PRROTECT at Ann & Robert H. Lurie Children's Hospital of Chicago for Oral Immunotherapy (OIT), which would attempt to desensitize her to her peanut allergies safely. Unbeknownst to the Tatelli family, however, of the nine children participating in each of the four trials, two were going to be chosen at random for the control group, and Susan was one of the children. The control group is the one in a trial or study that does not receive treatment by the researchers and is then used as a benchmark to measure how the other tested subjects do. Over the 30-month trial, Susan suffered nine anaphylactic reactions requiring treatment with the EpiPen, eight of which Susan was able to administer herself. Because Emergency Room visits are recommended after the administration of an EpiPen, Susan is very familiar with North Shore Highland Park Hospital and its Emergency Department.

"Emergency room visits after Epinephrine administration are necessary, because the symptoms can come back," said Jennifer Kim, MD, pediatric allergist at NorthShore University HealthSystem (NorthShore). "It's called a biphasic reaction, so we want to be sure the patient is under medical supervision."

The final results were positive and Susan has made steady progress since she entered the study in 2012 and is now in a 5-year follow-up study. Her off the charts 360 sensitivity rating has declined steadily and now stands at 56.8. She has since participated in other studies and sees a team of allergists in Chicago, on the North Shore and in the Fox Valley area.

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Susan Combines Discipline, Training and Creativity in All Her Pursuits

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In addition to her OIT, which includes the daily ingestion of peanuts to desensitize her, Susan also uses Xolair, an anti-inflammatory medication used to treat asthma that has been found to suppress reactions.

Susan has had amazing success taking on every challenge that has come her way. At the age 13 she enjoyed her first trip to an ice cream shop, at age 15 she celebrated her birthday with an M&M party and in the past year she passed her 24-peanut challenge with flying colors. And, as if she didn't have enough to do between school, scouting, speaking and being a teenager, Susan decided to take up figure skating, competing regularly throughout the Midwest.

Mom Caryn said she is, "very comfortable, the food allergy piece is no longer relevant." Her and her husband actually proved their point by taking the family on a Hawaiian vacation, and flying round-trip.

On the positive side too, according to Dr. Kim, 80 percent of children eventually outgrow most common food allergies, except for peanuts, fish, shellfish and sesame.

In recognition of her outstanding service and tireless efforts in spreading her message, that has included making and posting videos, speaking at numerous events and doing training sessions at middle schools, Susan has been earned several awards, including the Gold Award from Girl Scouts of the USA, the highest achievement within the Girl Scouts of the USA, and an award only 5.4 percent of Girl Scouts manage to earn due to the difficulty of the escalating level of projects that must be completed, Bronze, Silver and Gold. So, in her "Journey" Susan worked on a variety of projects, including providing books for the Nuestro Center in Highwood, providing a washer and dryer to Orphans of the Storm, an organization *Highland Park Neighbors* features in every issue, producing her "How to Stay Alive" videos, making her "So What" food footprint to inform food allergy sufferers on what they eat, where it comes from and what's in it, and for holding a Food Allergy Community Education day at Northfield Middle School.

"While some scouts complete their Gold Award or Eagle Scout project and that concludes their work in that area, for Susan, her Girl Scout Silver and Gold Award projects have been more the beginning than the end," her mom wrote in an email. "She continues to advocate, educate and demonstrate in her daily life, with the conviction that talking about anaphylaxis is the only way to save lives."

Susan has also been honored with the Character Counts Award at Highland Parke High School, presented to her by Mayor Nancy Rotering and she was asked to speak at two national



Always Carry 2!

food allergy conferences in the last year. Amanda Orlando who writes a blog for the Everyday Allergen Free website wrote, "This badass teen is educating youth about anaphylaxis." Her organic search results on Google are at the top of the page due to the comments, likes and shares she's received across Facebook and other social media applications.

Only a sophomore in high school and only 15 years old, Susan hasn't even really started thinking about getting driver's license, or where she's going to go to college, but each day she lives her life to the fullest and has packed so many things into so few years, that *Highland Park Neighbors* is sure we all be amazed at what she will accomplish in the future.

Please note: Susan is wearing red sneakers in her photos, because she has partnered with **Red Sneakers for Oakley**, a non-profit organization founded by the parents of Oakley Debbs to raise awareness about the dangers of food allergies. Oakley was 11 years old in 2016 when he suffered a fatal anaphylactic reaction resulting from a mild nut allergy. When she accepted her Gold Award, Merrill and Robert Debbs, Oakley's parents, sent the red Converse sneakers Susan wore with her dress to her. For more information about Red Sneakers for Oakley, visit <https://www.redsneakers.org/about-us>.

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