

THE 570 NETWORK: THE570 | BIZ | CALENDAR | CARS | CLASSIFIEDS | HOMES | JOBS | VARSITY | DIRECTORY | SUBSCRIBE • NEWSLETTERS

newsitem.com

Search site	Web search	Search local businesses
<input type="text" value="Enter a search term..."/>	<input type="button" value="Search"/>	
<input type="text" value="Enter a search term..."/>	<input type="button" value="Search"/>	
<input type="text" value=""/>	<input type="button" value="Search"/>	

HOME NEWS SPORTS OPINION ARTS & LIVING CLASSIFIEDS CUSTOMER SERVICE

ELECTION 2011 | BUSINESS | COURTS/POLICE | OBITUARIES | YOUTH & SCHOOL | ANTHRACITE OUTDOOR ADVENTURE AREA



Open a Way2Save® Savings account
\$1 automatically transferred from your checking account to your Way2Save account when you use your debit card.

Start Saving
Member FDIC

Together we'll go far

Rare disease nearly kills West Cameron Twp. man

BY MARK GILGER JR. (STAFF WRITER MARK_GJR@NEWSITEM.COM)

Published: August 15, 2011

ARTICLE TOOLS

SHARE | FONT SIZE: [A] [A] [A]

OUR SOCIAL NETWORKS 

FACEBOOK

SIGN UP NEWSLETTER



Larry Deklinski/Staff Photos The pink section on the hands of John Hornberger, of West Cameron Township, shows the area where Stevens-Johnson Syndrome affected his arm. Also shown are some of the medications Hornberger takes to control the rare disease, which affects a person's skin and eyesight.



John Hornberger, of West Cameron Township, recalls the day he was stricken with Stevens-Johnson Syndrome and almost died.

WEST CAMERON TOWNSHIP- It has been six years since John Hornberger, 56, of West Cameron Township, experienced unimaginable pain and nearly died from a disease that most medical professionals have never heard of before: Stevens-Johnson Syndrome. Today, Hornberger looks at the scars on his body with his partially damaged eyesight, and is determined to raise enough awareness about the rare disease to help others avoid the suffering he felt.

"It's only rare if you don't have it," said Hornberger. "I remember saying that if I could do anything to prevent this from happening to anyone, I wanted to be involved."

Stevens-Johnson Syndrome is an adverse drug reaction that causes painful blistering of the skin.

If left untreated, the skin literally melts off one's body. A person's eyesight is also threatened by the disease that causes severe conjunctivitis, iritis, palpebral edema, conjunctival and corneal blisters and erosions, and corneal perforation.

According the foundation's website, sjsupport.org, adverse drug reactions kill nearly 100,000 people every year, but less than 1 percent are reported to the Food and Drug Administration.

The disease can be triggered by ingredients found in simple over-the-counter medications. Hornberger's reaction was caused by Allopurinol, a medication he took for kidney stones.

Not poison ivy

In September 2005, John Hornberger was clearing land for his new home in West Cameron when he started to develop a rash. Thinking it was poison ivy, he ignored it for several days until he felt sick and his sister insisted he see a doctor. A foreign doctor, who was on duty at Shamokin Area Community Hospital emergency room, said the rash looked like a disease he had seen in his home country, Stevens-Johnson Syndrome.

Unable to be treated at the Shamokin facility, Hornberger was transported to Geisinger Medical Center in Danville while his sister, Ellen Reed, researched the disease online and found the Stevens-Johnson Syndrome Foundation.

"If it wasn't for Ellen, I wouldn't be here," he said. "I owe her so much."

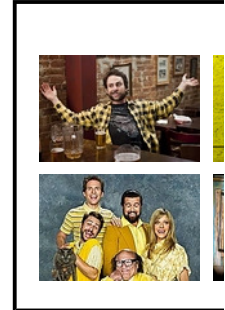
Reed said the doctors didn't pay much attention to what she told them about the disease and transported Hornberger by Life Flight to the burn center at the Lehigh Valley Hospital when Geisinger staff was unable to treat him.

"That's what the problem is," said Hornberger. "Even the doctors are unaware about the disease and don't know how to treat it. Had I known, I could have been treated in enough time and had no symptoms."

During the flight, Hornberger went into shock and after being revived, slipped into a coma for six weeks. He spent about two months in the burn center. About 95 percent of his skin melted off, the lining of his lungs were burned, his throat fused shut and the corneas of his eyes were burned. Doctors informed his family twice that he was going to die.

"It's just so draining mentally, physically, emotionally and spiritually. It was horrible," said Hornberger. "There was such a horrible smell. It smelled like death."

Doctors were eventually able to save Hornberger's skin, but the scars of the disease are evident all over his body. Hornberger



LATEST VIDEO

Bachmann offers her view
Reuters Aug. 29, 2011



1m20s

Bachmann offers her view on hurricane
1m20s

DSK retu IMF for meeting
1m21s

Now Playing

1 c

Most Read Most Comment

- Man trapped in car more crash on Rt. 42
- Flood causes first ever I cancelation
- Fair Canceled
- 3 more arrested in maile
- Six flood-damaged hom condemned in Shamokin

also underwent two operations to open up his throat.

"I couldn't talk or walk," he said. "It was frustrating for a 50-year-old to not be able to communicate."

The doctors also told him that he would eventually be blind.

"Most people who have the disease end up blind and deaf," said Hornberger. "I said, 'I don't think so; I'm going to see my grandson.'"

After 2 1/2 months of rehabilitation, Hornberger returned home, retaining a portion of his sight. He can see objects very close to him, but the edges of his sight are blurry.

"It's like I'm looking through a milk bottle," he said.

Raising awareness

Hornberger is convinced that he would not be alive today if weren't for the support of his family, his faith and the Stevens-Johnson Syndrome Foundation that provided him with information about the rare disease.

As soon as he could, he called Jean McCawley, founder of the Stevens-Johnson Foundation, to tell her that if it had not been for her foundation providing information about the disease, he would not be around to tell his story.

"We have to raise awareness," he said. "People have to know what it is and how to treat it and possibly save a life just by knowing what to do. It's not pretty, but people need to be aware that it can be caused by something as simple as taking Tylenol."

Medical professionals still do not know what causes the disease and there is currently no way to tell who is more likely to get it.

"It doesn't matter who it affects, kids to adults," said Hornberger. "People are taking more and more medications today and we are seeing it more and more."

One of the goals of the organization is to encourage research of the disease. Hornberger said that stem cell research may reveal more about the rare disease and there are other promising treatments for the disease that are pending approval for the market.

Hornberger is now one of 26 facilitators for the foundation throughout the world. He writes letters to local lawmakers every year, asking them to make August Stevens-Johnson Syndrome awareness month.

He also organizes a soup supper each year at St. Peter's Church, Herndon, to raise money for the organization. Hornberger said the supper raised close to \$900 dollars last year and is set for Nov. 12 this year.

"There's a saying that the organization likes to use: 'Find out about Stevens-Johnson Syndrome before it finds someone you love'," said Hornberger. "That saying is so true."

APMEX ® Gold Dealer Ads by Yahoo!
 Low Prices. Order Online 24/7! Changing How The World Buys Gold™.
www.APMEX.com/GoldCoins
Invest in Gold: Goldline®
 Gold Delivered to Your Door. Free Investor Kit. Since 1960.
Goldline.com/Gold
Buying Gold Made Easy
 Goldline - It's Simple To Buy Gold. FREE Gold Investment Kit -Act Now!
GoldlineGold.com

We welcome user discussion on our site, under the following guidelines:

To comment you must first create a profile and sign-in with a verified DISQUS account or social network ID. [Sign up here.](#)

Comments in violation of the rules will be denied, and repeat violators will be banned. **Please help police the community by flagging offensive comments for our moderators to review.** By posting a comment, you agree to our full terms and conditions. [Click here to read terms and conditions.](#)

Like 4 people liked this.

Comments for this page are closed.

Showing 0 comments

Sort by Popular now ✉ Subscribe by email 📡 Subscribe by RSS

Real-time updating is **enabled**.

comments powered by [disqus](#)

- [Sound Off 9-15-111](#)
- [Police Blotter](#)
- [Application process for in Northumberland Cour](#)
- [Flooding at Knoebels wi](#)
- [Flood hazards: Many da](#)

JOBS570

Paraprofessionals (Cataw

[More top jobs](#)

- [Sound Off 09-10-](#)
5 comments · 5 da
- [Reporter navigate from Sunbury to :](#)
4 comments · 6 da
- [Knoebels well-ve waters](#)
2 comments · 4 da
- [Sound Off 09-11-](#)
1 comment · 2 day
- [Sound Off 09-07-](#)
3 comments · 6 da

REALESTATE5

- 1 Coal Township
- 1 Kulpmont
- 2 Shamokin
- 1 Sunbury
- 2 Minersville

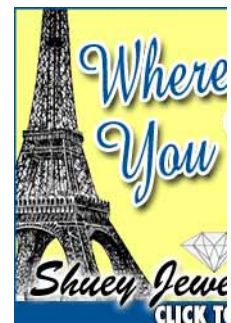
[More top homes](#)

- [Man trapped in car more crash on Rt. 42](#)
- [PEMA, FEMA open seve relief centers; closest in](#)
- [Flood causes first ever E cancellation](#)
- [Application process for in Northumberland Cour](#)
- [Zerbe schedules pickup trash](#)

CARS570

1995 Buick Le Sebre

[More top autos](#)



[NEWS](#) | [SPORTS](#) | [OPINION](#) | [ARTS & LIVING](#) | [CLASSIFIEDS](#) | [CUSTOMER SERVICE](#) | [OBITUARIES](#) | [HOME DELIVERY](#) | [PLACE AN AD](#) | [FIND SHAMOKIN JOBS](#)

News Services: [SEARCH ARCHIVES](#) | [NEWS ALERTS](#) | [ADVERTISE](#) | [SITE MAP](#) | [HELP](#) | [WORK HERE](#)

Copyright ©2011 The News Item | 707 N. Rock St. | Shamokin, PA 17872 | (570) 644-6397

[PRIVACY POLICY](#) | [OPINION POSTING POLICY](#) | [ABOUT OUR ADS](#) | Questions or comments? [CONTACT US](#)