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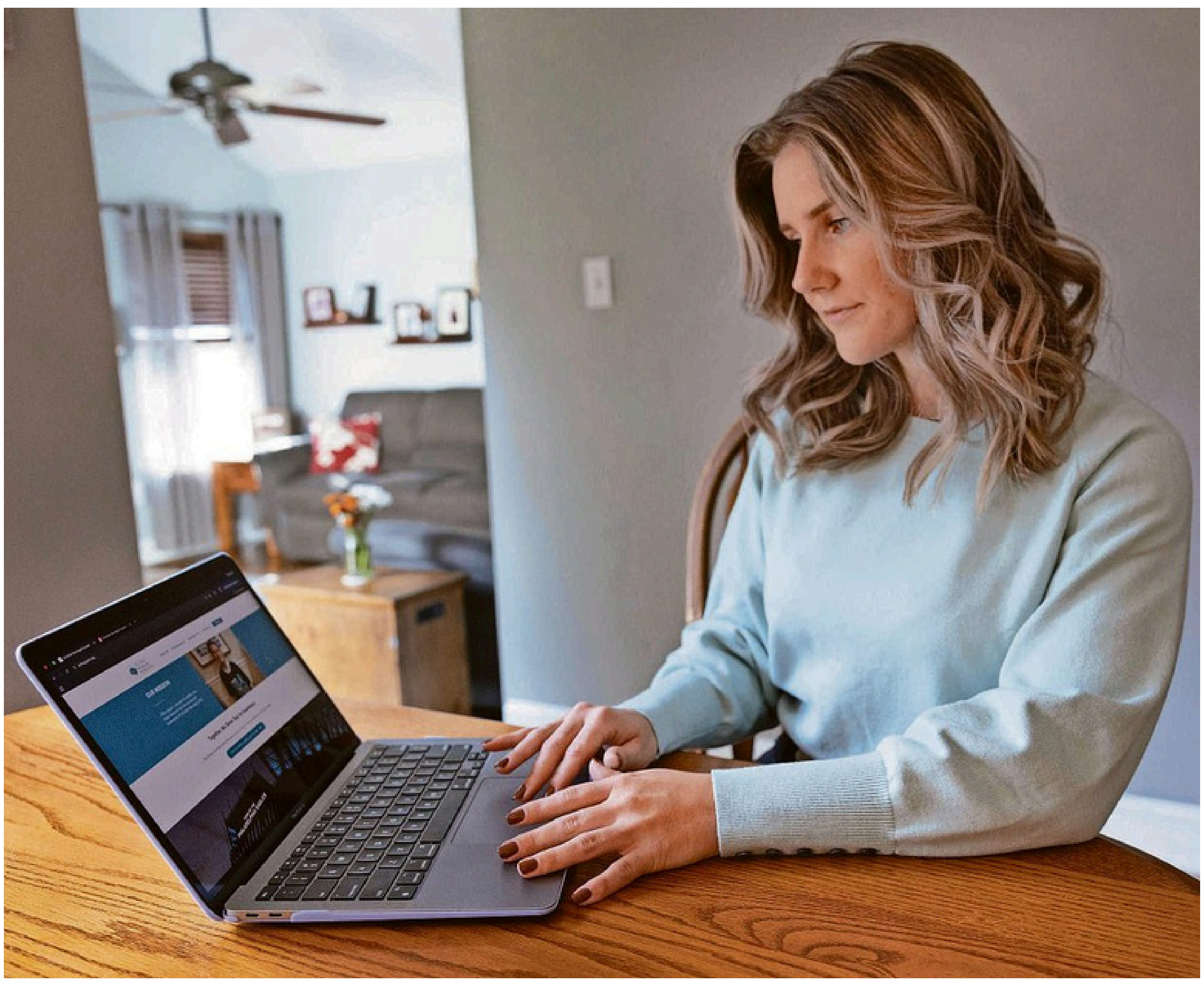
# Turning calamity into a good cause



**Kayla Smock is a 23-year-old Jackson woman who drew on her own experience with a brain injury to found a nonprofit focused on occipital neuralgia, a rare but painful condition that causes severe, piercing headaches.** PHOTOS BY PETER ACKERMAN/ASBURY PARK PRESS

## Woman was diagnosed with rare condition that causes headaches

**Carino's Corner**
Jerry Carino
Asbury Park Press
USA TODAY NETWORK – N.J.

Kayla Smock was 13 years old and playing for a travel softball team when she collided with a teammate while trying to catch a fly ball. The Jackson resident was diagnosed with a concussion, whiplash and a neck sprain.

"Doctors kept saying, 'just stay in a dark room and it will improve over time,' but my pain was not improving," Smock recalled. "There was a constant ache in my head, but I would also have these shooting pains that would radiate from the back of my head."

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> **"Concussions are often treated as routine, especially when you're young. Mine didn't resolve — and now I know why."**
>
> **Kayla Smock**

# Trump doubles down on asylum freeze

## President says 'no time limit' on application processing pause

**Thao Nguyen**
USA TODAY

President Donald Trump doubled down on his anti-immigration policies on Nov. 30, saying his administration's pause on the processing of all asylum applications has "no time limit, but it could be a long time."

"We don't want those people. We have enough problems," Trump told reporters on board Air Force One. "Many of them are no good and they shouldn't be in our country."

When asked who "those people" are, the president clarified, "people from different countries that are not friendly to us and countries that are out of control themselves."

He again referred to "Third World Countries," a term used to refer to poor and less developed nations.

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# Union Beach mom seeks new trial

## Woman serving 100-year sentence for 1994 arson murders of toddlers

**Kathleen Hopkins**
Asbury Park Press | USA TODAY NETWORK – NEW JERSEY

FREEHOLD – A Union Beach woman, serving a 100-year prison term for killing her two toddlers by setting them on fire in her car, is seeking a new trial after almost 30 years, claiming she was convicted of the murders on the basis of "junk science."

Attorneys from the New Jersey Public Defender's Office have asked Superior Court Judge Jill Grace O'Malley to grant a new trial for Maria Montalvo, 61, saying the state's expert testimony about where the deadly fire started would no longer be admissible in court. They say fire science has evolved to the point where the theories put forth by those experts have since been debunked.

Prosecutors don't dispute that, but argue there was adequate other evidence for a jury to convict Montalvo of her children's murders.

O'Malley, who conducted a hearing on the motion for a new trial on Oct. 22, has not yet issued a decision.

In a case described by police and prosecutors as one of the most gruesome they had ever seen, Montalvo's two youngest children, Rafael Aponte, 28 months, and his sister, Zonaida Aponte, 18 months, were burned to death inside Montalvo's Volkswagen Jetta outside their grandmother's Long Branch home on Feb. 22, 1994.

Montalvo, then 29 and a nurse at Rahway Hospital, doused the interior of the car with gasoline and ignited

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# Wall to switch to Monmouth EMS despite public opposition

**Erik Larsen**
Asbury Park Press | USA TODAY NETWORK – NEW JERSEY

WALL – In a contentious meeting held two days before Thanksgiving, the Township Committee voted 4-0 to effectively disband the township's professional emergency medical service (EMS) and join Monmouth County's MedStar system.

The vote came despite a standing-room-only crowd of residents and EMS employees, and a rare public rebuke from the township's own police chief regarding the transparency of the process.

Mayor Timothy J. Clayton abstained from the vote, citing an unspecified conflict of interest. The decision will dissolve the Police Department's EMS division, established in 1999, but does not affect the township's two volunteer squads, Community and Wall.

Under the new arrangement, Monmouth County MedStar will provide "roaming ambulances" that are not tethered to a specific station. Tobia sought to assure the public that the county would maintain a minimum of two ambulances in Wall Township at any given time.

Township Administrator John W. Tobia framed the decision as a fiscal necessity. He warned that without switching to the county service — which will be free to the township — the municipality would face a deficit that could force staff reductions in other departments, including the police force.

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# Carino

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**Kayla Smock, 23-year-old Jackson woman, drew on her own experience with a brain injury to found a nonprofit focused on occipital neuralgia, a rare but painful condition that causes severe, piercing headaches. Kayla (center) is seen with her parents Ryan and Cathy Smock on Nov. 28.** PETER ACKERMAN/ASBURY PARK PRESS

Two years passed until a sports medicine doctor determined the problem to be occipital neuralgia, a painful condition in which the occipital nerves — the nerves that run through the scalp — are injured or inflamed. It took two more years and her mother Googling another patient's blog to find a solution – nerve decompression surgery.

So for four years, "I was confined to my bedroom, bedridden, I was in so much pain," said Smock, who had to be home-schooled as a student at Jackson Memorial High School. "I was a very happy kid, outgoing, athletic – and all of that changed quickly."

Her head hurt so badly, she couldn't run a comb through her hair. Even resting her head on a pillow proved painful. Perhaps the hardest part was the reaction of much of the medical community.

"My doctors often said, 'No one has a headache 24/7 – you're just an anxious teenager, making this up for attention,'" Smock said.

She wasn't, but there was scant information available about occipital neuralgia.

The condition is uncommon, but far from unheard of – a 2021 study determined that 25 percent of 800 patients at the Cambridge Headache Clinic in Massachusetts suffered from it.

Smock became determined to spread the word about this and help others cope. Now, a decade after that softball collision, she's turned a calamity into a success story.

## 'Kayla is a life-saver'

Early on after her diagnosis, Kayla searched Facebook for occipital neuralgia support groups.

"I needed people to talk to who understood this pain," she said.

"There were a couple groups out there, but most were very depressing. People did not want to live anymore – they were at an end with their pain. I wanted to reframe that and create something more positive for people, offer people hope." So she launched her own social media platform, and by 2020 the initiative became the Occipital Neuralgia Foundation, a nonprofit whose website www.onfsupport.org features patient stories and in-depth interviews with three surgeons about the condition. "We're touching people all over the world, which has been incredible," Smock said.

The website has been viewed by over 100,000 visitors. For some of them, it's made a profound difference. Florida resident Alyssa Turner came across the site when trying to find help for her 11-year-old daughter Olivia, who fell ill in 2022. "We basically had hit every dead end and had maxed out all of our resources – no providers had any more information for us," said Turner, who is a nurse. "She was starting to significantly lose the quality of her life at age 8."

The Turners connected with one of the surgeons featured by the Occipital Neuralgia Foundation, Dr. Ivica Ducic, and Olivia underwent nerve decompression surgery in December 2023. Now Olivia is "back to doing dance and soccer," Alyssa said. "She has virtually no restrictions."

As Alyssa Turner explained it, because occipital neuralgia doesn't turn up on an MRI, sufferers often mistakenly get treated for migraines - or sometimes anxiety and depression – and are prescribed medicines that don't work or make things worse.

Karla Gronsdahl, a 59-year-old resident of British Columbia, Canada, incurred occipital neuralgia from a car accident in 2023 and was diagnosed in 2024.

After coming across the Occipital Neuralgia Foundation she was treated by another surgeon featured on its website, Dr. Ziv Peled.

"I feel like I'm myself again," said Grondshal, who is a retired college administrator. "Kayla is a life-saver, putting that website up. I want to do everything I can to help Kayla and her foundation get known."

The nonprofit's latest success story is the publication of a thesis by Dr. Merel Hazewinkel, the first doctoral student in headache surgery.

The foundation contributed financially to the dissemination of the report, which focuses on improving patient selection and outcomes in nerve decompression surgery for neuralgia. It can be read in full at www.onfsupport.org.

## 'Be your own advocate'

Kayla Smock's transformation from bedridden accident victim to leader in the occipital neuralgia community is not all that surprising to those who know her.

"She's an inspiration," said Patricia Golden-Gartner, a longtime family friend who lives in Neptune. "She started this foundation because that's who she is. Her middle name is kindness."

Smock recently moved to Florida, where she works full-time in marketing for a company specializing in nerve repair. Her immersion in the field is complete. She's still living with pain – a constant level three or four on a 1-10 scale, compared to a constant nine for the first four years after the collision. The residual pain likely results from four years having elapsed between her injury and the surgery, she said. But she's not complaining, given where she's been.

"I'm doing really well now," Kayla said. "I never thought I'd be able to live this life." Smock's biggest piece of advice for anyone in chronic pain?

"Don't be afraid to speak up for yourself and be your own advocate," she said. "We put so much faith in the medical community, which we should – they are incredible – but we also need to listen to our body and we need to listen to our gut. I was repeatedly told 'you just have a concussion – deal with it.' But it was my parents who really advocated for me."

She visited her parents, Cathy and Ryan Smock, in Jackson over Thanksgiving weekend. There was much to be thankful for.

"I struggled for a long time asking the question, 'Why did this happen?'" Kayla said. "I was so young and it was just a collision. Now I know this all happened for a reason. When my mom found the blog about the decompression surgery, I remember how hopeful we felt in that moment. It makes me so happy that I could be that person for someone else."

*More information about the Occipital Neuralgia Foundation can be found at the website www.onfsupport.org, on Facebook at www.facebook.com/occipitalneuralgiafoundation, or on Instagram at www.instagram.com/occipital.neuralgia*

*Jerry Carino is community columnist for the Asbury Park Press, focusing on the Jersey Shore's interesting people, inspiring stories and pressing issues. Contact him at* jcarino@gannettnj.com.