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Volunteers walk in La Grange Highlands to raise awareness of genetic kidney disease

By HANK BECKMAN
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FEEDBACK

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Residents of the La Grange Highlands turned out in force Sunday morning to stage a walk to promote awareness of Polycystic Kidney Disease on Oct. 17. (Nicole Shehan / HANDOUT)

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Residents of the La Grange Highlands turned out in force Sunday morning to stage a walk to promote awareness of Polycystic Kidney Disease (PKD), an illness that has afflicted their neighbor, David Ninesling, since he was a young boy.

“He was diagnosed with PKD in the eighth grade,” Joy Ninesling, David’s wife, said before the walk.

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Volunteer Walk Coordinator Nicole Shehan said that about 200 people gathered at the La Grange Highlands Elementary School and walked for about an hour through the neighborhood before ending at the Ninesling residence.

PKD is an inherited disease that affects 600,000 people in the United States, according to the web site of the National Kidney Foundation.

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PKD causes clusters of cysts to form primarily in person's kidneys, although they can also form in the liver and pancreas.

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The disease causes the kidney's to enlarge and lose function over time. PDK also can cause End Stage Renal Failure, colon complications, heart problems, and kidney stones.

Ninesling had a kidney transplant in 2008 and for the last two years, he has been on dialysis.

His original replacement kidney was ultimately rejected and he recently spent 24 days in the hospital. Ninesling, in his fifties, still has hope for something resembling a normal life.

“He’s looking for a second transplant,” Joy Ninesling said.

The PKD Foundation’s web provides an overview of the Foundation’s history, goals, and success raising money for research for a cure for PKD. Since its founding in 1982, the Foundation has raised \$50 million and leveraged \$1.5 billion in government funding.

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Of the total raised, \$33 million came from the Walk for PKD, a national event founded in 2000.

The web site walkforpkd.org highlights some of the successes of the walks, and is the main resource available for those who wish to donate to the cause.



Residents of the La Grange Highlands turned out in force Sunday morning to stage a walk to promote awareness of Polycystic Kidney Disease (PKD). (Hank Beckman / Pioneer Press)

In 2020 alone, the walks raised \$2.87 million toward funding research grants. This year's walk had about 50 events and drew 10,000 participants hoping to reach the goal of \$1 million.

To that end, the walkers from the La Grange Highlands top the list this year, with \$31,000 raised, about half of the total money raised from the Chicago area.

The volunteers included La Grange Highlands students and other area youths who made signs for the walkers to navigate the neighborhood on the way to the Ninesling residence.

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"It was a beautiful day," Shehan said, "and they're still counting the money."

Shehan pointed out that the money raised was all the more remarkable since the La Grange Highlands Walk was only organized two weeks ago. The rapid success had everything to do with the way the neighborhood feels about the Ninesling family.

"We're all out here supporting this wonderful family," Colleen Narbone said. "They were always praying for their father in church."

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Kellene O'Connell, who organized the walk, echoed Narbone's sentiments.

"This community loves this family so much," she said.

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For Shehan, it's crucial to get the word about PKD.

"The biggest part is raising awareness," she said, pointing out the hereditary nature of the disease. "It just keeps getting passed down. There's no cure, but there is

hope.”

Further information on Polycystic Kidney Disease can be found at the PKD Foundation’s website: pkdcure.org.

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