Ulman house will give young adult cancer patients a place to stay

The Ulman Cancer Fund for Young Adults, which provides support services to young people with cancer and their families, is building a house in Baltimore where patients 15 to 39 can stay while receiving life-saving cancer treatments.

Andrea K. McDanielsContact ReporterThe Baltimore Sun

House for adolescent cancer patients to be built in Baltimore



After Dan Ellis underwent a bone marrow transplant for leukemia at the <u>University of Maryland Medical Center</u> in 2013, doctors recommended he stay near the hospital during recovery because he would have frequent followup visits and was at high risk for complications.

Ellis had stopped working as a bouncer in <u>Ocean City</u> when he became ill and couldn't afford to stay in Baltimore near the hospital, he said. Instead, he lived with his parents in Frederick and made the nearly hour-long drive to the city several times a week.

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Ellis' mom had to rush the now 31-year-old to the emergency room in Baltimore on three separate occasions; once when he was throwing up blood, and twice when he came down with pneumonia and began shaking violently. He collapsed at the hospital two of those times because he couldn't breathe and was placed in intensive care.

"It is a reality that if you have had a transplant you are more than likely going to have some time when you have an issue and are going to need to get to the hospital quickly," Ellis said. "But I didn't have the money to live any closer."

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Young <u>cancer</u> patients who face the same dilemma soon will have a place to stay in Baltimore. The <u>Ulman</u> Cancer Fund for Young Adults, which provides

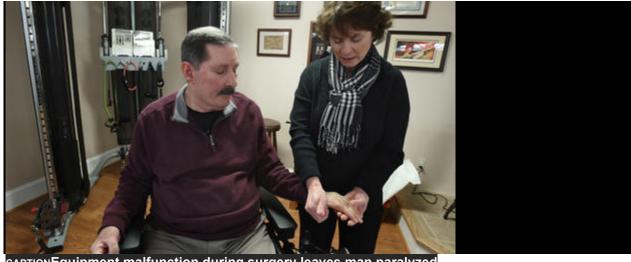
support services to young people with cancer and their families, is building a house in Baltimore where patients 15 to 39 can stay while receiving life-saving cancer treatments.



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"Housing is critical," said Brock Yetso, executive director of the Baltimore-based advocacy group. "Just a 30-minute drive when you have to be in the hospital every single day can be very challenging. A patient who doesn't have close housing might bypass treatment. They might go somewhere closer to home where the treatment is not the same."

Founded in 1997 by three-time cancer survivor Doug Ulman, brother of former Howard County Executive Ken Ulman, the nonprofit broke ground Friday on the conversion of six abandoned row homes on Madison Street near <u>Johns Hopkins Hospital</u> in East Baltimore into the temporary living space.



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It will cost about \$1.25 million to renovate the row homes and cover operating costs for three years. The group has raised about \$750,000 of that money. Administrators expect it will serve 250 patients and their families a year.

Cancer occurs more frequently in adolescents and young adults ages 15 to 39 years than in younger children. About 70,000 people of those ages are diagnosed with cancer in the United States each year, and they are often diagnosed with different types of cancer than either younger children or older adults, according to the National Cancer Institute, the federal government's principal agency for cancer research and training.

Scientists are not sure why, but young adults tend to get more aggressive forms of cancers and may need more intense treatment. While children are more likely to get hereditary cancers and adults lifestyle influenced cancers, young adults get a mix of the two. They are more likely than either younger children or older adults to be diagnosed with Hodgkin's lymphoma, melanoma, testicular cancer, thyroid cancer, and sarcoma, the cancer institute reported.

And not all doctors know how to treat young adults. Typically children get more aggressive treatment because their bodies are younger and can bounce back. Until recent years, some doctors would not treat young adult cancers the same because they worried they couldn't handle it and instead treated them more conservatively like older adults.

One researcher in 2003 described the group as the "lost tribe." The lack of attention on young adults has resulted in stagnant survival rates, unlike the improved cancer survival rates in children and adults, according to doctors.

"Once you get a spotlight on these patients, you realize there are a lot of challenges," said Dr. Kenneth R. Cooke, director of pediatric bone marrow transplant at the Johns Hopkins Kimmel Cancer Center.

Now doctors are trying to learn more about caring for young adult cancer patients. Changing treatment styles help explain why young adults need so much monitoring during treatment, doctors said.

"It is not uncommon when somebody is diagnosed with a complicated cancer that they may make 100 visits for treatments and follow-up scans and tests," said Dr. Kevin Cullen, director of the University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center. "It is an unbelievably draining time commitment. And if you travel any type of distance it can be tough. The ability to stay close by and be able to afford it is a tremendous, tremendous help."

In Baltimore, the Ronald McDonald House offers housing to about 1,400 children up to age 21 and their families each year.

Yetso said there were not really options for anyone else.

Sandy Pagnotti, CEO of the Ronald McDonald House Charities of Baltimore, said there is a need for more housing services for cancer patients. The organization has plans for an expansion of its own. It will break ground on a new building on West Fayette Street later this year. The new building should help the group almost double the number of patients and families it now serves.

"The more resources we have to support these families, the better it is for everybody," Pagnotti said.

Baltimore has highly ranked cancer centers, including the Greenebaum and Kimmel cancer centers, that attract patients from all over the state and country.

Pagnotti said the Ronald McDonald House also is seeing many patients from the Maryland Proton Treatment Center, which opened last year. The center is affiliated with the University of Maryland School of Medicine and uses precisely targeted radiation treatment on the toughest cancers.

The Ulman foundation got input from cancer patients such as Ellis when designing the new house.

The house will include eight private family suites on the top floor and a communal living space on the main floor. It will also include a 1,000-square-foot meditation room and wellness area.

"Patients and survivors said these are the things they wanted to see," Brock said. "They wanted it to be useful and medically safe, but not childish."

Ellis hopes the new house will make life easier for the young people who will stay there so that they don't have to go through the same obstacles he did during treatment.

"It's going to be a huge burden lifted off of people," Ellis said.

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