

Friends of Patients at the NIH Many helping one. One helping many. The Friends of Patients at the National Institutes of Health provide Hope by giving emotional financial support to patients receiving groundbreaking and life-saving treatments at the NIH.

## Meet Joshua, Michelle and Lauren - NIH patient and his family....

Joshua has been at NIH every six months for the last 15 years for routine care. Diagnosed at eight years old, he has x-linked chronic granumolous disease, a hereditary disease in which certain cells of the immune system have difficulty forming pathogens. This means that certain immune cells do not function properly to kill some types of bacteria and fungi, leading to ongoing and severe infection.



Now, at 23 years old, Joshua has been a resident patient in the

Clinical Center since May 2016. After complications from a stem cell transplant, Joshua is bed bound. It is hard to express how devastating this is. For the last six months, his mother and fiancée have been with him constantly, sleeping in his hospital room or in a rental apartment, as they both reside in Arkansas. The emotional support this provides is critical, but it comes at a very high cost.



After many months of uncomfortable sleeping arrangements and draining their savings to pay theirs and Joshua's rent and utilities expenses in Arkansas while they were at NIH, Joshua's mother Michelle and his fiancée Lauren were connected with Friends of Patients at the NIH. After hearing their story and understanding the circumstances, Friends at NIH was able to provide them

with living arrangements at the new Friends apartment at the Flats 8300 Apartments in Bethesda, MD. Located close to the NIH campus and with the comforts of home, the apartment is offered to qualifying patients and their families rent-free for both short and long term use. Now Michelle and Lauren can cook their meals rather than eating out, shower at reasonable times and get a full night's sleep.

With their new living arrangements, Melissa and Lauren are close to the Clinical Center and can get there in a short amount of time which is important as one of them has to be present for "rounds" each morning to advocate for Joshua as a result of his condition. When asked about the effects of residing at the apartment, Lauren said "I'm much more relaxed. I like to be at home a lot so the apartment feels like a home rather than a hospital room or hotel." "It's really a big relief to feel comfortable and feel like you are in your own place," added Michelle.

On a regular basis, Friends of Patients at the NIH provides hope and healing to families just like Joshua's. There are currently three apartments as well as several long-term-stay hotels that provide families much needed relief as they face both financial and

## Belfort Furniture Gift

## BELFORT FURNITURE

Friends of Patients at the NH is delighted to announce a new gift from Belfort Furniture. This gift provided all of the furniture for both of the two new apartments at the Flats 8300 Apartments in Bethesda. Beds, dressers, tables, sofas, chairs-the whole worksmade these two new apartments truly "homes" for patients and families who need short or long term housing while undergoing treatment at the Clinical Center. Matt Huber, Executive Vice President of Belfort Furniture, said "Our contribution to Friends of Patients at the NIH to make housing comfortable and inviting is a small token of our appreciation for the groundbreaking treatments they provide."

It turns out that the Huber Family has a special connection to NIH's Clinical Center. Matt Huber's sister Lauren was diagnosed 15 years ago with an uncommon cancer during her senior year of high school. Lauren was fortunate to receive daily outpatient treatment at NIH with an innovative radiation technique that was not available anywhere else. The treatment worked, and Lauren remains friends with her radiation nurse to this day.

Remembering this experience and how Lauren and the entire family responded during the treatment, Matt truly understands how important it is to have a comfortable place to return to after treatment. When he learned about the project to furnish two apartments for patients and their families, he knew that he had to help. Working together on this project not only directly serves NIH patients, but is aligned with Belfort's mission "to enhance the lives of the people and community we serve."

To view furnishings Belfort Furniture can provide, visit <u>http://www.belfortfurniture.com</u>

For more information about ways to make a gift, please contact Heidi Grolig at groligh@mail.nih.gov.

## 2016 Friends Night Out

Please join us for the Friends 2016 signature gala to be held on Thursday, October 13 at Stella Barra/Summer House (11825 Grand Park Avenue in North Bethesda, MD) from 6-9pm. Tickets are \$125.

This special evening brings together community members, patients and NIH leadership to celebrate Friends of Patients at the NIH's commitment to serve patients and their families. We hope that you will be with us to celebrate all of the important work you have made possible. It promises to be a wonderful evening with new and old Friends. For more information and to register, please <u>click here to visit our website</u>.



Friends of Patients at the NIH provides support for patients at the NIH Clinical Center by offer financial assistance for housing and utility expenses, access to respite care and support for travel costs. Friends champions NIH patients, helping to cover their essential needs so they can focus on recovery, healing and their unique role in health discoveries.

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