

#### 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.

# Friends and families making an impact. Meet Ana and her legacy...

To honor daughter and wife Ana Longenderfer Dougherty after her death in 2015 from cancer, Roger and Michele Longenderfer, her parents, and Chris Dougherty, her husband, turned to Friends at NIH. The families created Ana's Impact, a fundraising project to benefit NIH patients through their partnership with Friends of Patients at the NIH. Roger recalls the conversation including "How do we keep her energy and intelligence going? That was the birth of Ana's Impact."

To date, the families have raised over \$110,000 to support patients and families receiving treatment at the NIH Clinical Center. Through the *Friends of Patients at the NIH*, these funds have supported a variety of initiatives, including:



- Enhancements to the arts and crafts program in the Clinical Center, focusing on patients who are in isolation and confined to their rooms for long periods of time, increasing their budget by 60%.
- Local outings for patients and their caregivers including movies, dinners out, and visits to the mall to lift their spirits and provide respite.
- Household and decorative furnishings for the two new Friends at NIH patient apartments at Flats 8300, located just down the street from the NIH campus. Ana's Impact is also paying for one of the apartment's rent and maintenance costs.

Ana truly believed in the NIH clinical trials. She hoped more people could experience the NIH and its healing mission. In looking for a partner for their project that reflected Ana's goals, Roger says, "I wanted to find someone who would recognize the importance of what we were trying to do in Ana's memory. We came across the Friends of Patients at the NIH." And the partnership to honor Ana by helping other NIH patients came to life. Through the Longenderfer and Dougherty family's generous commitment of fundraising and outreach, the Friends of Patients at the NIH is able to help even more patients and families that need hope and healing. In honoring Ana this way, the Longenderfer and Dougherty families have truly made an impact for so many.

To read more about Ana and her lasting Impact click here

## Faith and Hope: Meet Martha Chavez, Aparicio





"The support I've gotten by Friends of Patients has been incredible; they are always on top of things... At the moment when I mostly needed it, they were able to help me, they were able to secure me an apartment at the Monterey, and truly it was at the right time, because the resources start to evaporate, and then it is difficult." Martha Chavez Aparicio

Over the last several years, Martha and her family have been helped by Friends of Patients at the NIH several times - receiving support for housing and travel as well as respite care for her and her family. Martha was diagnosed in 2012 with pre B-cell Acute lymphocytic leukemia (ALL), a very acute form of leukemia, in her early 40s. A native of Bolivia, Martha was initially cared for there. But when her doctors there could no longer help her, she was referred to NIH.

During her treatment, Martha had three stays at the Clinical Center, far from her family, home and support network. Her initial stay was when she received her stem cell transplant and Friends of Patients at NIH helped her family with housing at the nearby Monterey apartment so that her daughter and sister could remain close and visit daily. She recovered well from the transplant and was able to return home.

Martha was readmitted to NIH less than a year later. This time, her husband traveled with her and cared for her. With the family solely dependent on Martha's husband's income, the financial burdens of international travel, additional medical expenses, the family home in Bolivia, and their needs in Bethesda became overwhelming. Again, Friends at NIH provided housing for the family close by as well as helped with groceries. Martha and her family were even able to take an outing for dinner and movie provided by Friends at NIH - a much needed respite. Stable and strong, Martha again returned home to Bolivia.

Last summer, Martha once again relapsed and returned to the Clinical Center. She planned to enroll in a new outpatient protocol that involved growing donor cells within her cells in the lab. It turned out that Martha was not a good candidate for the protocol. Not strong enough to fly back home to Bolivia alone, Friends of Patients at the NIH flew Martha's husband to Bethesda to bring her home one last time.

Sadly, on the morning Martha and her husband were to leave the NIH, she took a significant turn for the worse. Later that day, Martha passed away peacefully with her husband and daughters by her side.

Heidi Grolig, CEO of Friends of Patients at the NIH, spoke with Martha the day before she passed away, as she was packing her things to return home. Martha shared that she felt truly blessed that she was able to come to NIH and try all the different treatments that they could offer. She felt that even if the treatments didn't save her, she felt at peace

knowing that what they learned from her disease would someday help save someone else's life.

### Preschoolers benefit from peanut allergy therapy



Peanut is one of the most common causes of food allergies. Allergic reactions to peanut can be mild, but they may also be severe and lead to a life-threatening allergic reaction called anaphylaxis. Peanut allergy usually starts in early childhood and lasts a lifetime. Avoiding exposure is the best way to prevent an allergic reaction. But steering clear of peanut is difficult, since it can be in foods you may not suspect.

Recent studies have shown that an experimental treatment called oral immunotherapy can reduce allergies to some foods, including peanut. A team of researchers led by Dr. Wesley Burks at the University of North Carolina at Chapel Hill tested the approach as an early intervention in preschool-age children newly diagnosed with peanut allergy. The work was partly supported by NIH's National Institute of Allergy and Infectious Diseases (NIAID) and National Center for Advancing Translational Sciences (NCATS). Results were published online in the Journal of Allergy and Clinical Immunology on August 10, 2016.

The team enrolled 40 young children (9 to 36 months old) newly diagnosed with peanut allergy. The treatment involved eating small, gradually increasing amounts of peanut protein each day. ....*Read More* 

"This study provides critical evidence supporting the safety and effectiveness of peanut oral immunotherapy in treating young children newly diagnosed with peanut allergy," says NIAID food allergy expert Dr. Marshall Plaut.

Researchers continue to monitor the participants to assess how long the treatment effects may last. Scientists note that this experimental therapy is still being tested in clinical trials and should be given only under medical supervision. Consult with a doctor before giving peanut products to an allergy-prone child.

#### Click here for the full story.



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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