



# #INN2025, The Inn's New Strategic Plan

Changes and improvements are coming to The Inn, and we're excited to tell you about them. We've just launched our new strategic plan, #INN2025, that will serve as The Inn's roadmap for the next several years. If you're envisioning a dusty binder on a shelf, think again! Our dynamic plan is the product of diligent research, inspired planning and fresh thinking that aims to accelerate The Inn's impact on medical discovery and care.

Significant advancements in clinical care, hospitality and technology compelled our board of directors to begin the strategic planning process early last year. Throughout the 16-month process, we researched health care and hospitality trends, examined our families' needs and the barriers they encounter to clinical trial participation, and – (Continued on back panel)

# INNspirations

SUMMER 2018

The Children's Inn at NIH

## Mission Statement

The Children's Inn at NIH will fully and consistently meet the needs of children and families participating in ground-breaking research at the National Institutes of Health.

We will:

- Respond to evolving family support needs from pediatric research and clinical care
- Provide a free family-centered "place like home"
- Reduce the burden of illness through therapeutic, educational and recreational programming

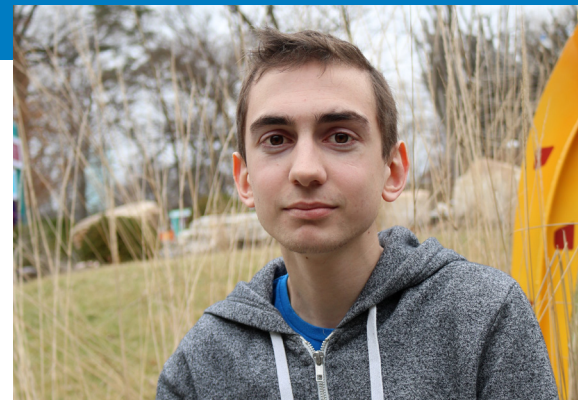
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## Harnessing Immune Power to Knock Out Leukemia



Felix Weimar is one of the NIH patients receiving CAR-T cell therapy for leukemia.

Today, most children diagnosed with acute lymphoblastic leukemia (ALL), the most common childhood cancer, are cured. Yet some young patients don't respond to chemotherapy, and in others, the cancer returns, sometimes again and again. Looking for new options for these patients, scientists have unveiled cancer immunotherapy, which strengthens the body's ability to eradicate cancer using its own immune system.

At 20 years old, Felix Weimar of Vienna, Austria, has had cancer half his life—first diagnosed with acute lymphoblastic leukemia, or ALL, at age 9. Four times, the cancer came back, and he's endured multiple, punishing rounds of chemotherapy, radiation and two bone marrow transplants.

Amazingly, that's changed for the better. In summer 2015, he received CART-T cell therapy at NIH as part of an experimental clinical study, and since then his leukemia has vanished.

"It's remarkable—the dramatic results we're seeing with CART-T therapy," says Dr. Nirali Shah, a physician researcher at the National Cancer Institute who is conducting the study and is Felix's NIH doctor. (Continued on page 2)



Manahil Ahmed, 22, of Canada is one of a growing number of children and young adults staying at The Inn to undergo CAR-T immunotherapy.

## Harnessing Immune Power to Knock Out Leukemia

(Continued from front panel) CAR-T therapy is an approach called adoptive cell transfer. What that means is that doctors use a cancer patient's own immune system—one of the most powerful disease-fighters known to medicine—to attack his or her own cancer like it would an infection.

Being treated with CAR-T therapy is very different from swallowing a pill or getting chemotherapy through a vein. CAR-T cells are customized for every individual. When Shah first sees a young patient with ALL, the first step is a blood test to see if the child's tumor cells are recognizable to supercharged immune cells. If they are, Shah explains, she removes immune cells from her patient, and the cell processing team weaponizes the immune cells (T-cells) by attaching a chimeric antigen receptor, or "CAR," whose job is to seek out and destroy cancer cells.

The process of making custom CAR-T cells takes about 10 days, enough time for the "living drug" to grow and then be injected back into the patient. Somewhat counter-intuitively, when Shah's patients start feeling bad and spiking fevers, she knows the treatment is working. That's because feeling ill is the body's response to the immune system getting activated. For Shah's patients, other lab tests can actually track the growth and movement of the powered-up cells inside her patients, as well.

Felix is used to feeling terrible after receiving traditional therapies, but CAR-T therapy didn't bother him too much. After he felt the immune "storm," the evidence of his tumor being attacked, he quickly recovered.

"The next day, I felt great and ate my favorite breakfast of sunny-side eggs and toast," he says. He's getting on with life, attending college and studying biotechnology.

In May 2016, Manahil Ahmed, 22, went to the emergency room for leg and lower back pain that wouldn't go away. Prescription painkillers didn't help. Further blood tests revealed she had ALL. Manahil started chemotherapy, but her cancer came back. As with Felix, she also got a bone-marrow transplant and relapsed again.

In early February 2018, she received CAR-T therapy at NIH, which worked to get rid of her leukemia, and she continued to study, write and watch college lectures remotely from The Inn whenever possible. Unfortunately, Manahil recently found out her cancer has returned, but she hopes that research will lead to another option for her and others.

Although the very first pediatric immunotherapy recipient treated elsewhere has now been cancer-free for almost six years, as with Manahil, not all patients have had continued benefit from CAR-T therapy. Yet a 2018 study in the *New England Journal of Medicine* showed that within three months of treatment, 80 percent of children receiving CAR-T therapy had no detectable cancer.

Currently, all patients getting CAR-T therapy are those people whose cancer has come back or who have developed new tumors. Someday it may be used earlier in the treatment course, as a "first-line therapy."

For now, young cancer patients like Felix and Manahil who come to NIH and The Children's Inn are brave pioneers in an exciting time of medical progress. The NIH care team—nurses, dieticians, social workers, doctors, and others—watch over these special patients 24/7 to monitor the treatment and keep them comfortable.

And The Inn makes it all a lot more bearable, says Shah: "The work we do takes a village—all our patients support one another."

"We couldn't do our work without The Inn." ★



Farrah Mackenzie and her dad, Andy, were this year's Evening for Hope featured speakers.

## A Historic Evening For Hope Gala

It was a momentous evening at An Evening for Hope, an annual gala benefitting The Children's Inn, which raised over \$1,000,000 for the first time in the event's history. The sold-out gala brought together 800 Inn supporters, including NIH leadership, federal technology and health care industry leaders, and corporate partners to The Ritz-Carlton Tysons Corner for food, drinks, live and silent auctions, and live entertainment.

Inn children and families had a strong presence at the event as Farrah Mackenzie, 12, along with her father Andy, spoke to guests about the challenges of living with a life-threatening illness. At two years old, Farrah experienced health complications involving her lungs and was diagnosed with a primary immune deficiency disorder. While staying at The Inn, she underwent chemotherapy and a bone marrow transplant at the NIH.

"I have made a bunch of friends at The Inn," Farrah said. "If it were not for the NIH, I might not have a new immune system. And if it were not for The Children's Inn, I couldn't have come to the NIH, so I feel really lucky to have found both!"

Donning a superhero cape, Inn resident Jordan Larocco, 7, mingled with attendees and helped sell raffle tickets on behalf of The Inn. News anchor Tony Perkins, FOX 5 News, emceed the evening, and guests enjoyed live entertainment by musical talent and "The Voice" contestant Brandon Showell during the after-party.

The Inn would like to recognize top-tier sponsors NETE, Booz Allen Hamilton, GDIT and Leidos for their support of the event. ★

## Over A Decade of Involvement for Deloitte Consulting

Deloitte Consulting has been supporting The Inn for more than 10 years - and what a difference that support has made! Most recently, Deloitte teams have been helping with two pro bono projects, one focused on program evaluation and another on the family experience, both of which will inform our programming and services for years ahead.

Deloitte's comprehensive support for The Inn touches all facets of our operations: whether advising on governance or diversity and inclusion, initiatives that were led by long-time Inn board member and past board chair Kelvin Womack who leads Deloitte's Federal Human Capital project, or IT services, hosting family dinners, or sponsoring each of our signature events, Deloitte employees are regularly seen in our hallways. In fact, each summer a large team of Deloitte volunteers converge on The Inn for the firm's annual Impact Day, a firm-wide volunteer service day that celebrates Deloitte's year-round commitment to community organizations.

This year, leaders from Deloitte's federal government services practice, including Dan Helfrich, Government and Public Services Leader, visited The Inn for an afternoon of meetings, community service and brainstorming ways The Inn can further its role as a partner in discovery with the NIH—and had more than a little bit of fun. Beth Meagher, Federal Strategy Leader, explains: "Our relationship with The Children's Inn is so important to Deloitte. We are constantly seeking ways to help them achieve their goals because the work they do is so critically important to families and children getting treatment at NIH." ★



Leaders from Deloitte's federal government services practice pose with Inn CEO Jennie Lucca (left of center) during a day of innovative brainstorming and meetings.



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There are many ways to support The Children's Inn, such as food drives and the Thoughtful Treasures mailbox program. Visit [www.childrensinn.org](http://www.childrensinn.org) and click on Get INNvolved to learn more about how you can help the many children and families who call The Inn home.

Follow us on:

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## #INN2025, The Inn's New Strategic Plan

(Continued from front panel) with appreciation that input from our stakeholders was paramount to the plan's success - interviewed nearly 200 individuals representing Inn families, staff and board members, donors and NIH leaders and clinicians.

This engaging and educational process illuminated a few key strategic areas of focus from which three bold goals were developed. By 2025, we're committed to achieving:

- A state-of-the-art "smart" living environment
- Strong support programs that better integrate discovery and care
- A diverse group of leaders, supporters and volunteers ensuring The Inn's financial viability

Our work over the next several years will encompass a diverse set of activities, from master facility planning and renovation, to implementation of new technologies, to taking a fresh look at our business model. #INN2025's goals and objectives are complex, but its underlying principle is straightforward: we want to do more good for our families.

We look forward to sharing our progress with you as we move forward.

To see the latest news about #INN2025 and read a summary of the plan's goals and objectives, visit our #INN2025 website at [childrensinn.org/INN2025](http://childrensinn.org/INN2025). ★



Thr #INN2025 strategic plan will enhance the family experience for years to come.