

TRANSFORMING LOSS INTO

ADULTS WITH LYMPHOMA

No parent should ever have to go through the excruciating experience of losing a child. When Ellen M. Walker lost her only son, Paul, to lymphoma in 2012, she was devastated. She channeled her grief into creating The Paul Foundation to support young people and their families facing a lymphoma diagnosis so that no one has to go through what she and her son Paul endured.

Paul Walker Schaffel was a 21-year-old senior at Wesleyan University in 2011 when he noticed his swollen glands. It wasn't long before Paul's symptoms worsened, including night sweats, extreme fatigue, and loss of appetite. He returned home to New York to seek medical care, where he was first diagnosed with Hodgkin lymphoma and eventually non-Hodgkin lymphoma. Paul underwent his first round of chemotherapy in December 2011. While in treatment, he continued his studies and graduated with honors in the spring of 2012. In the same year, Paul was accepted to Harvard Law School but succumbed to non-Hodgkin lymphoma before the start of his first year.

Before he died, one of Paul's final wishes was for his mother, Ellen, to create a foundation to fund research and raise awareness of non-Hodgkin lymphoma so that other young people and their families could get the help they needed. In Paul's memory, Ellen created The Paul Foundation, a nonprofit with a mission to fund non-Hodgkin lymphoma research and provide those affected by the disease, their families, and healthcare professionals with the tools to identify, treat, and cure non-Hodgkin lymphoma.

"During Paul's final days, it became clear to him that he was going to die," Ellen explained. "He wanted to go home while he still could, and about two days before he died, Paul gathered his friends and family and gave each of us a job or two to do. Paul asked me to create a foundation in his name to help make sure that what happened to him would not happen to anyone else. And that's how The Paul Foundation came to be."



"I'm always thrilled and delighted to talk to survivors who have beat lymphoma. I wish I had a survivor of my own, but I don't. So now this is my job. I've got to talk it up. I've got to say his name." —Ellen M. Walker

Drawing on her expertise as a practicing attorney in New York, as well as unwavering persistence, Ellen established The Paul Foundation in September 2012. She immediately began raising money to fund research and raise awareness of lymphoma in adolescents and young adults (AYA)—an often underserved and understudied population. One of the early steps she took was to connect with the Lymphoma Research Foundation (LRF). In September 2013, The Paul Foundation made a \$400,000 contribution to LRF to honor Paul and became a Founding Sponsor of LRF's Adolescent and Young Adult (AYA) Initiative, which aims to support the lives of young people diagnosed with lymphoma. LRF honored The Paul Foundation with the Distinguished Service Award at the LRF 2014 Annual Gala.

"We are proud to be the Founding Sponsor of LRF's AYA Initiative to honor Paul's wishes and to create a new mechanism for funding research, which is so important when it comes to learning more about and developing new treatments to address lymphoma in young people," Ellen explained. "LRF immediately understood our vision and shared our goal to establish dedicated lymphoma resources specifically for adolescents and young adults."

On a personal level, Ellen says The Paul Foundation and her work with LRF provides her with the opportunity to give back, talk about her son in a positive way, and have others keep his memory alive. Since its inception in September 2012, The Paul Foundation has committed almost \$1 million toward its mission.

"LRF has been a fantastic partner, and it's been gratifying to see the AYA Initiative grow. Young adults continue to be an underserved population, but there are now researchers who study lymphoma as it relates specifically to Paul's age group. That was not the case when Paul was diagnosed with lymphoma—so that's progress!"

Today, Ellen resides in Florida and spends most of her spare time raising money to fund lymphoma research, from hosting charity dinners to donating to LRF. When she's not keeping Paul's name alive through her work, you can find her on a tennis court.

Ellen's hope is that The Paul Foundation and LRF can help even one mother, like herself, avoid the pain and sadness she endured.

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To learn more about The Paul Foundation, visit **pwsfoundation.org/**donate

A cancer diagnosis is unexpected, especially for adolescents and young adults (AYAs) in their teens, 20s, and 30s.

The Lymphoma Research Foundation (LRF) is dedicated to assisting young lymphoma patients and survivors with addressing the unique medical, psychosocial, and access challenges they may encounter by providing support, resources, and programs.

RESOURCES FOR AYAS:

- Peer-to-Peer Support
- Lymphoma Facts & Guides
- Digital Education & Tools
- In-Person Education & Networking Programs
- LRF Helpline

Visit **lymphoma.org/aya** to learn more.