

NF NEWS



THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
WINTER 2022

More than 400 people came together in person and virtually this July for the first annual NF SUMMIT in Chicago, Illinois. Those who gathered defined themselves in many ways: individuals living with NF, advocates caring for NF patients, NF clinicians and researchers, and representatives from NF organizations, academic institutions, pharma, and industry — a community committed to ending NF!

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NF SUMMIT Attracts NF Patients, Clinicians, Families, and Pharma

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This summer's inaugural NF SUMMIT was an educational and networking conference that evolved from CTF's annual NF Forum and Volunteer Leadership Conferences, which have taken place for over a decade. Those annual meetings built the necessary foundation for a new, dynamic, inclusive event intended for anyone with a connection to NF. In the spirit of new, there were 212 newcomers – more than 50% of those in attendance were first-time attendees. Tandy Wolters and Michael Peper were among this group, present as parents of NF Hero Leo and volunteers dedicated to learning and building their leadership skills.

“Michael and I had the most amazing time. It was just incredible, all parts of it, especially meeting other families. We are hopeful. We loved it.”

TANDY WOLTERS
MOM OF NF HERO, LEO

The NF SUMMIT also brought together over 50 speakers covering a wide range of content from chronic pain to using social media to raise awareness and build community. Of those speakers, 36 had never before attended or spoken to the NF community at a CTF event. One of those exciting newcomers was Dr. Charles Argoff, Vice President of Scientific Affairs at the American Academy of Pain Medicine (AAPM), who said, “On behalf of the

AAPM, I want to thank you for inviting me to participate in your annual meeting. The energy at the meeting, as well as during the panel discussion, was incredible.”

Additionally, NF organizations from around the country came to Chicago for the NF SUMMIT, including NF Midwest, NF Network, NF Northeast, NF Texas, Littlest Tumor Foundation, NF Team, NTAP, University of Alabama NF Clinical Trials Consortium, and members of the NF Collective. Another important NF organization, B the Difference, generously donated financial scholarships through their ‘B Kind’ program so several NF patients could attend in person.

Representatives from Lurie Children's Hospital, Stanford Medical Center, and Massachusetts General Hospital were present and recruiting for clinical trials relevant to the NF community. Connecting patients to researchers is something CTF is passionate about, and we are excited to grow these opportunities at future events.

The NF SUMMIT was generously supported by Alexion AstraZeneca Rare Disease, as well as SpringWorks Therapeutics, NFlection Therapeutics, Recursion, and Healx.

NF SUMMIT 2023 will take place June 21-24, 2023 in conjunction with the NF Conference in Scottsdale, Arizona. To learn more, go to nfsummit.org



Make NF Visible Recognition Awards 2022

Make NF Visible Community Recognition Awards acknowledge individuals or groups, at every level of involvement, who Make NF Visible in the local community, nationally, or globally. These awards recognize a diverse group of committed people who work tirelessly throughout the year to help CTF fulfill its mission. Award presentations took place at a special reception on July 22, 2022, at the NF Summit in Chicago, Illinois.



Volunteers of the Year, Diane Owens and Lara Mukabenov

2022 Make NF Visible Recognition Awardees

Volunteer(s) of the Year:

Diane Owens and Lara Mukabenov

Community Advocate Award:

Naomi Cuka

Clinician Award:

Tena Rosser, MD

Young Leader Award:

Maddie Sassa

Patient Advocate Award:

Dale Berg

Researcher Award:

Kevin Bruemmer, PhD
Young Investigator Awardee

Corporate Champion Award:

Bourbon Charity

Global Reach Award:

Magda Chlebus

Fight NF Your Way Award:

Mark Ehrli

Honorable Mention Award:

McKinnon Galloway