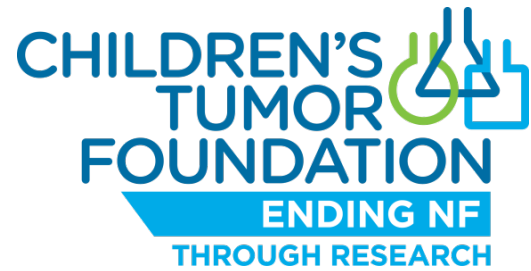
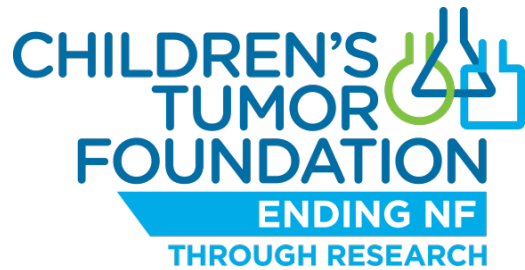


Patient Engagement Program  
Director, Traceann Rose



## A brief history of patient engagement



# CTF PATIENT ENGAGEMENT MODEL

## 1. Patient Training and Education

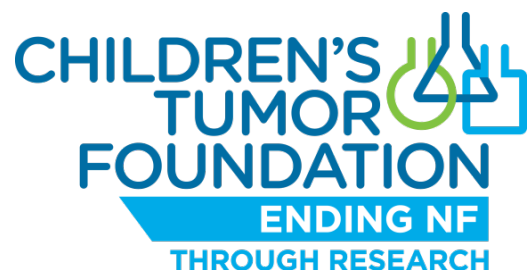
- we expect patients to learn about the value of being involved in research and expand their knowledge base.

## 2. Patient Participation in Research

- focus on actively participating in REiNS' and CTF's research programs

## 3. Shared Knowledge Through Partnership

- engagement with industry, regulatory affairs, and other stakeholders to provide stakeholders a better understanding of the impact of NF on patients and their families.



# PATIENT TRAINING AND EDUCATION

2018 NF Forum



**CHILDREN'S TUMOR FOUNDATION**

**NF Patient-Centered Outcomes Research (NF-PCOR) Forum**

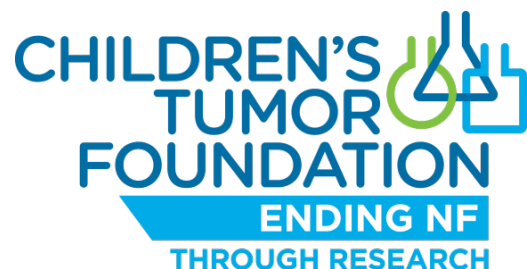
**MAY 4-6, 2018, ATLANTA, GEORGIA, Hilton Garden Inn, Downtown**

The NF Forum is a fun family weekend in which patients, caregivers, and children come together to:

- get support and network
- meet experts in the field of NF
- find out how to get involved in patient-centered research

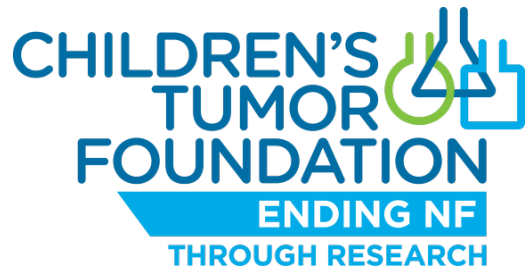
Registration opens January 15, 2018 - go to [ctf.org/nfforum](http://ctf.org/nfforum)

TO LEARN MORE CONTACT [Traceann Rose, trose@ctf.org](mailto:Traceann.Rose@ctf.org)



## PCORI Funding Acknowledgement

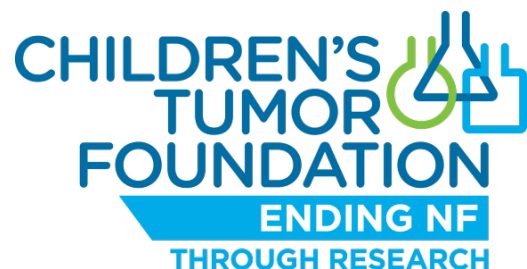
*This NF Patient Centered Outcomes Research Forum is partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EAIN-7142)*



# CTF PATIENT REPRESENTATIVE PROGRAM

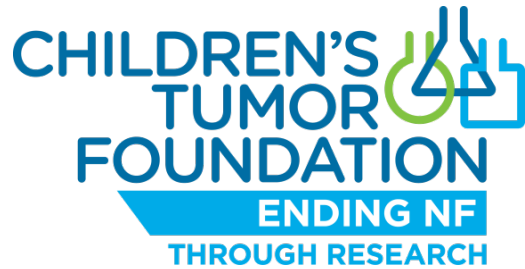
To increase the capacity of patients to participate in research.

- First cohort of Patient Representatives recruited in September
- In-person training in May at the NF Forum
  - Training will cover topics spanning research, protection of human subjects, drug development and about NF and CTF
  - All representatives will receive a certificate of participation upon completion of the in-person training
  - Long-term objective training program is patient engagement with industry, regulatory affairs, and other stakeholders, to provide stakeholders a better understanding of the impact of NF on patients and their families.



## How does CTF's patient program complement the REINS initiative

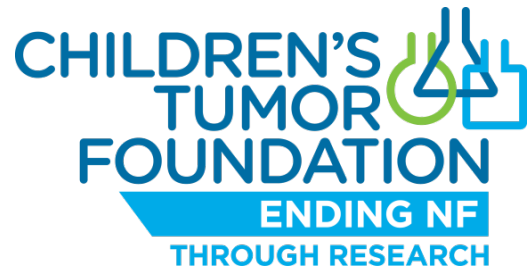
CTF's program is a foundation program to train patients to become patient experts/advocates and participate in research and advocacy opportunities such as REINS.



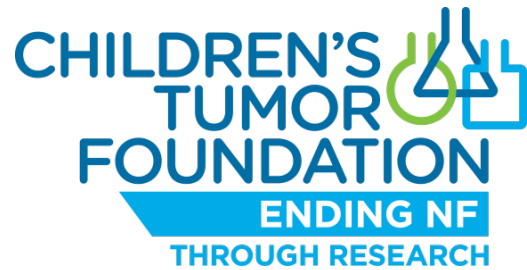
## SHARED KNOWLEDGE THROUGH PARTNERSHIP

- Patients Help Doctors/Researchers Network (PHD)
  - Trained patient partners will be established to integrate clinicians and all stakeholders, fostering continuous interactive communication across all groups, and accelerating the research recruiting process.
- REINS
- Central Patient Involvement Resource on CTF website





## A patients perspective on involvement in research



Thank You!

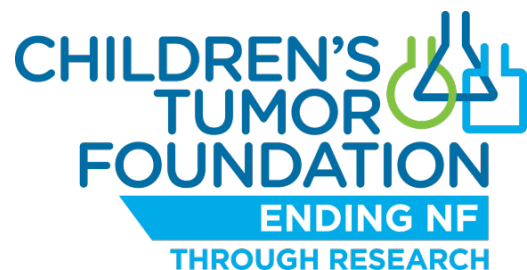
For more information contact

Traceann Rose, Director Patient Engagement

Children's Tumor Foundation

E: [trose@ctf.org](mailto:trose@ctf.org)

Ph: 212-344-6691



**YOU ARE INVITED TO ATTEND!**

2018 NF Forum



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