



Children & Youth with Special Health Care Needs National Research Network

FOR IMMEDIATE RELEASE

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New Guide Helps Ensure Patients and Families are Fairly Compensated for Partnering with Research Teams

“As a parent, it was validation. I not only had a seat at the table, but was considered an equal partner.”
~ Yetta Myrick, Family Partner

Aurora, Colo (Jan. 10, 2022) – If a youth, family, or patient agrees to be a co-investigator in a research study, should they be compensated? The answer is yes. Yet until recently, no guidance existed on how much to compensate a family partner.

A collaborative effort between the Children and Youth with Special Health Care Needs National Research Network (CYSHCNet) and the advocacy group Family Voices resulted in the most comprehensive guidance to date. The *Standards of Compensation for Youth, Family, and Patient Partners* walks through common roles the research partners may serve and what’s expected of them.

The guidance helps youth, families, and patients better understand the levels of support, compensation, and reimbursement they can expect to receive. It also helps researchers and funders by outlining sample budgets and ranges of compensation.

Yetta Myrick is a family research partner. She feels grateful for this guidance.

“I was first paid to serve on an advisory board in 2013. Previously, I had been invited to serve on many boards but they were all volunteer and unpaid,” she said. “I remember the Principal Investigators on the project made it a point to share that they were paying all of the board members, whether they had a PhD or not, the same rate per hour to serve. As a parent, it was validation. I not only had a seat at the table, but was considered an equal partner.”

Engaging patients and their families as full partners in research is fundamental to making research better. The guidance is a game changer for everyone involved.

“Many funders are now requiring that those who are most affected by research be involved as co-investigators on studies, but there has been no guidance on compensating research partners for their lived experience and the many hours they invest in working on studies,” Shelton said. “We



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hope this guide helps both researchers and partners equitably work together to advance science for the benefit of all patients and their families.”

The *Standards of Compensation for Youth, Family, and Patient Research Partners* is available as a free resource through CYSHCNet. There is a version for investigators and a version for research partners, available in English and Spanish.

[Download the guide.](#)

Questions about how to use this guide? [Contact us.](#)

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About CYSHCNet

Children and Youth with Special Health Care Needs National Research Network (CYSHCNet) is a national group of expert investigators, family leaders, and early-career researchers. Our vision is to improve the health, wellbeing, and quality of life of children and families by creating and promoting research excellence. The network partners with families and collaborates to share findings and train early-career investigators.

About Family Voices

Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities. We connect a network of family organizations across the United States that provide support to families of CYSHCN. We promote partnership with families at all levels of health care—individual and policy decision-making levels—in order to improve health care services and policies for children.

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