



2022-2024

# Impact Report

# Educate Advocate & Support



# Content



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# Who inspires you?

I was asked this recently at a professional meeting, filled health and social care providers. The person who came to mind immediately was 20-year-old Louis (name changed), who cares for his parent while also caring for his siblings. He is deeply involved in helping his parent get around the home and community, managing their overall care, appointments, and medications.

He is quiet, kind, and focused. He is also weary. He knows every day is a new one, and perhaps a difficult one. I met him at a YCare session, where he and his siblings attended to learn more about caring for their parent, to meet other youth like them, and to have fun. Always a carer, he made sure his parent was cared for, so all the siblings could attend YCare. He moved through the day asking detailed questions, taking notes, and relaxing into the support. He didn't have to worry about his siblings who were with other youth their own age, as they were also asking lots of questions, and frankly, laughing a lot.

He inspires me.

At GNYC, we are inspired by the quiet work, resolve, and love young carers have for their family members. We are inspired by their parents and grandparents who ask the questions about how to talk about illness and the best ways to support their children. They inspire us to educate, support and advocate for young carers around the globe. They inspire us to make sure that laughter and joy are present, that the weary does not outweigh love, and the siblings' bonds are strengthened and nurtured.

We have hosted three YCare sessions in the past year, providing support and education to young carers across the US and Canada. These sessions included primarily Spanish and French-speaking communities, where we were able to adapt the materials and program in these languages. In addition to our other translations, we now have the LUKi™ coloring book available in Arabic, the first but not the last resource we will translate to Arabic, reaching a large and underserved community. Additionally, we partnered with ALS Canada to create a genetics guide for families, which was also translated to Spanish and French – extending our reach and acknowledging young carers are in all populations, across regions, and need education and support regardless of the language they speak or where they live.

None of this work would happen without two key things: our amazing partners and you, the individuals who donate to GNYC. In a changing world, we know there are increasing opportunities for giving. That you choose to give to us to support young carers is not lost on us.

Your donations have allowed us to extend our reach, create more print and online materials across language and culture, connecting us in a way we never were before. The families we support inspire me to keep moving forward, to keep building resources and programs.

Who inspires you? Let us know who inspires you, share what they do to inspire you and let's keep the inspiration traveling the globe.

## Melinda S. Kavanaugh, PhD

Founder & Board President

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## Mission

The mission of Global Neuro YCare is to **EDUCATE** through the creation and translation of materials and programs for children, youth and families; **ADVOCATE** with national and international organizations to guide the creation of regional, cultural and country-specific programming; and **SUPPORT** research addressing the needs and experiences of young carers.

## Vision

We envision a world where every family including children, youth, and young adults caring for a person living with a neurological condition has access to education, resources, and support reflective of their culture and language.

# 160+

Children & youth have participated in YCare

# 130+

Providers trained to facilitate YCare



Materials translated into **10+** languages

# GNYC Origins

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GNYC was established to address a critical and often overlooked need: the lack of resources and support for young caregivers of individuals with neurological conditions.

Grounded in years of clinical practice and research, the organization was born out of our body of evidence and direct experiences that revealed just how many children and youth are stepping into caregiving roles, over 5 million just in the US. One young caregiver had a profound impact that started it all. She told us:

"If someone says, 'how's your mom doing?' I'll say, 'Oh, she's doing all right.' But maybe, it'd be nice if someone asked me how I'm doing..."

~Young carer of a parent with Huntington's Disease

Everything we create is guided by a deep commitment to inclusion, equity, and evidence-based care. We honor the languages, cultures, and lived experiences of the families we support, while holding ourselves to the highest ethical standards. Our work is rooted in research, built for accessibility, and grounded in the belief that even in the hardest moments, joy and connection matter.



## Research: It's in our DNA

Research isn't an afterthought—it's our foundation. From the very beginning, our work has been built on the lived experiences of young caregivers, data, and evidence.

Everything we do is designed with rigor, equity, and participant dignity at its core—because ethical, inclusive research leads to stronger solutions.



# Programs







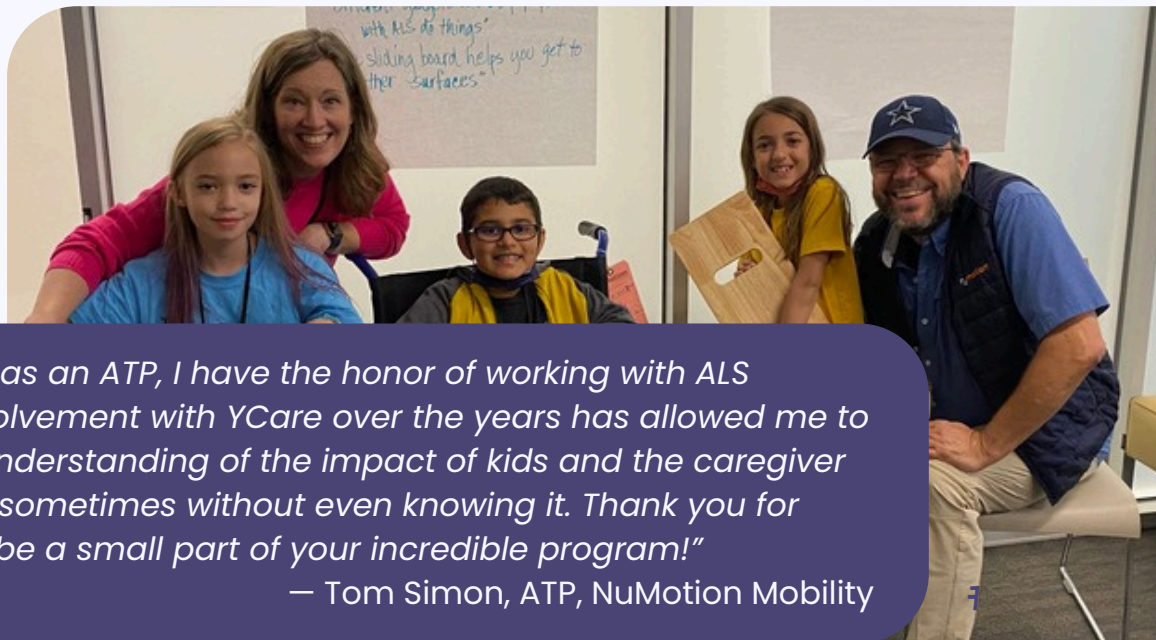
YOUTH CAREGIVING: TRAINING, SKILLS & SUPPORT

YCare is GNYC's flagship program. YCare is the only hands-on, research-informed program designed to teach young caregivers the skills, knowledge, and confidence they want and need; across conditions, across the globe.

### Program Outcomes:

- **Improved self-efficacy in care tasks** – increase young caregivers' self-efficacy and practical competency in performing complex care tasks, thereby enhancing the safety and quality of care provided.
- **Ability to identify self-care goals and coping behaviors** – empower young caregivers to develop and implement effective self-management strategies for their personal well-being, fostering resilience and mitigating caregiving-related stress.
- **Changed perceptions of care** – shift young caregivers' perceptions of care tasks from daunting or unclear to manageable and understandable, reducing anxiety and increasing their sense of capability.
- **Peer connection and support** – provide a supportive community for young caregivers, facilitating meaningful peer connections and alleviating feelings of social isolation.
- **Provider education** – provide opportunity for health and allied health providers to learn about and support young carers across illness and injury

YCare is setting the standard for caregiver education, equipping young carers and providers with practical tools and emotional support that make a real difference.



*"In my practice as an ATP, I have the honor of working with ALS families. My involvement with YCare over the years has allowed me to have a better understanding of the impact of kids and the caregiver role they serve, sometimes without even knowing it. Thank you for allowing me to be a small part of your incredible program!"*

— Tom Simon, ATP, NuMotion Mobility

***“The program is comprehensive without being overwhelming, there are opportunities for peer-to-peer learning and building confidence. The program and booklet give attendees a take-home resource which can be shared further or referred back on when in doubt. The program focused on empowering caregivers and reinforcing the importance of their role.”***

~YCare Facilitator

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## **Health Conditions & Communities We’ve Served**

Because of YCare’s modular curriculum, we are able to adapt it, specifically meeting the needs of young caregivers across conditions such as:

**ALS/Motor Neuron Disease**

**Autism Spectrum Disorder**

**Parkinson’s Disease**

**Cancer**

**Traumatic Brain Injury**

Additionally this adaptability allows us to support communities in a way that’s meaningful to them, including:

**Spanish-speaking families coping with ALS**

**Military & veteran connected youth**

**Youth in rural & under-resourced areas**

**Caregivers in South Africa, including translating materials into Sesotho & Zulu**



From the foods we demonstrate with to the way we form peer groups, every detail is thoughtfully considered. A session in a rural North Carolina school might look different from one with refugee families in New York City—and that’s by design.

This is what inclusion looks like in action. When young caregivers see their lived experiences reflected in the content so they can engage, learn, and feel valued. And it doesn’t stop there. We are on a mission to support young caregivers across the globe.



# Resources

In collaboration with families, healthcare professionals, and global partners we create books and materials to help children and families better understand neurological conditions and the caregiving journey. These resources are designed to open up conversations, build knowledge, and provide comfort.

**20+** translations of our books and resources are currently available

## Partner Case Study – Support for Military & Veteran families

When the Elizabeth Dole Foundation (EDF) identified the urgent need to better support youth caregiving for service-connected injuries and illnesses, they turned to GNYC. Known for our adaptable, research-informed approach and deep commitment to elevating young caregivers, GNYC partnered with EDF to co-develop responsive tools and supports for military & veteran families along with the providers and coalition of organizations that support them.

EDF needed a trusted partner to help support “Hidden Helpers,” children and youth in caregiving roles within military and veteran families that speak to their lived experience. The complexities of conditions such as spinal cord injury, traumatic brain injury, and PTSD required a trauma-informed, family-centered lens.



To meet these needs, together we created the Hidden Helpers Activity Book. Building on our successful LUKi & the Lights framework, we co-created an activity book designed specifically for children in military families. This tool fosters emotional expression and normalizes caregiving experiences in an accessible, age-appropriate way.

Additionally, the Hidden Helper Journey Map was created to visualize the caregiving path. GNYC facilitated the creation of an interactive Journey Map that traces the experiences of Hidden Helpers over time.

GNYC's partnership with EDF demonstrates what's possible when research, empathy, and community voice come together. By listening closely, designing collaboratively, and adapting our core model to new contexts, we continue our mission to ensure that young caregivers everywhere are visible, valued, and supported.



Journey map  
for older youth caregivers



Activity book  
for younger children caregivers



## LUKi & the LIGHTS<sup>®</sup>

LUKi & the Lights is a powerful, nonverbal animated film that explores the emotional journey of a family navigating a neurological condition made partnership with the ALS Association and Big Grin Productions Using visual storytelling without language barriers, the film resonates with audiences worldwide and has been screened in over 20 countries.

**10,000+**  
views in  
20+ countries

**40+**  
honors won across  
**95+** film festivals

# For Professionals



**“As clinicians, we rarely have the opportunity to connect directly with youth caregivers in our day-to-day work, yet their impact is visible everywhere—from the personalized messages they help add to a communication device to the creative ways they help troubleshoot tech challenges at home...”**

~ Cat Kanter, MS, CCC-SLP &  
Abby Marx, MS, CCC-SLP  
Bridging Voice

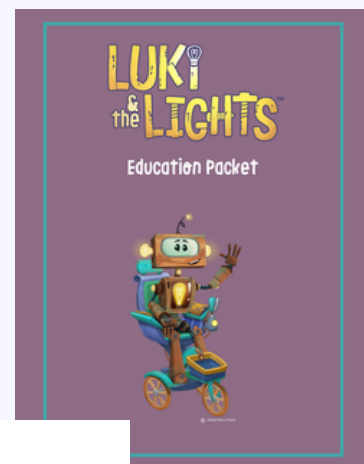
We know that creating systems change to support young carers must include education and resources for professionals. That’s why we speak at conferences, deliver workshops, and facilitate trainings across the U.S. and internationally, helping professionals understand the complex realities of neurological illness within families.

To extend the learning opportunities and accessibility, we also create practical tools such as our School Guide for Professionals created with the ALS Association, and the LUKi & the Lights Education Packet, designed to help educators, clinicians, and community leaders engage and support young caregivers in meaningful ways.

Through these efforts, we are shaping a global network of professionals committed to recognizing and supporting young caregivers as vital members of the care team.

**"I worked in a hospital for 16 years and never thought of this young caregiver perspective"**

~ Caregiving Symposium Participant





# Financials



# Our Fiscal Story

Built for Impact, Designed for Growth

GNYC is not a new idea—it's a proven approach, newly independent and we are poised to grow.

GNYC was founded on a deep commitment to youth caregivers and their families across the globe. While our formal 501c3 status is new, our work is grounded in over a decade of research, field testing, and real-world application.

Our flagship program, YCare, began with seed funding through the University of Wisconsin–Milwaukee and the ALS Association in the mid-2010s, with founder Dr. Melinda S. Kavanaugh at the helm. Once the YCare workshop was developed, it naturally expanded, supported beyond ALS into Alzheimer's and Related Dementia, and siblings of those living with autism. Chapters of the ALS Association, Aurora Health Care, and the United Community Center covered the direct program costs for workshops with personnel and research funded through UWM by Dr. Kavanaugh's external grants.

In 2022, we formally launched Global Neuro YCare as a nonprofit. Support from the ALS Association helped us to create LUKi & the Lights!, our animated short film for young carers. This marked the start of our transition from an academic initiative to an independent, mission-driven organization.

As our programming continued to expand in various communities and conditions to support youth caring for loved ones with spinal cord injury, traumatic brain injury, dementia, and other conditions, we have developed two funding models:

- Community-led model: Local partners fund the direct costs to bring YCare to their communities.
- GNYC-led model: We secure grants and philanthropic funding, then collaborate with trusted community organizations to deliver programming.





Both models ensure we are flexible and meeting partners where they are—financially and culturally. In all cases, we prioritize shared ownership and sustainability.

We’ve also continued to collaborate with UWM to secure research and project grants—such as funding through the Advancing a Healthier Wisconsin initiative, and the Elizabeth Dole Foundation—allowing us to maintain academic integrity, retain IRB approval, and continue building research efforts.

Today, GNYC operates with a lean and effective infrastructure. In our first full year of operations (2023), we completed and premiered LUKi & the Lights!, a foundational and resource-intensive project. This significant investment is reflected in our 2023 Form 990.

As we transition from a startup phase into strategic scaling, our financials naturally reflect the shift. We’re thankful for funders that are coming alongside to support GNYC’s growth. We’re also in the process of expanding our team and moving all core program funding from our university-affiliated research roots directly under GNYC. This shift will take time to be fully visible in our year-over-year financial reporting.

Your support ensures youth caregivers have the tools they need to thrive, no matter the diagnosis in their household.

To review our financial documents, please visit [globalneuroycare.org/financials/](https://globalneuroycare.org/financials/)





# Funding Partners



# Translation Partners



ALS Vietnam

Individuals:  
Zahieh Khweis  
Samantha Y Banda Palacios

# Program Partners



ALS Vietnam





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