

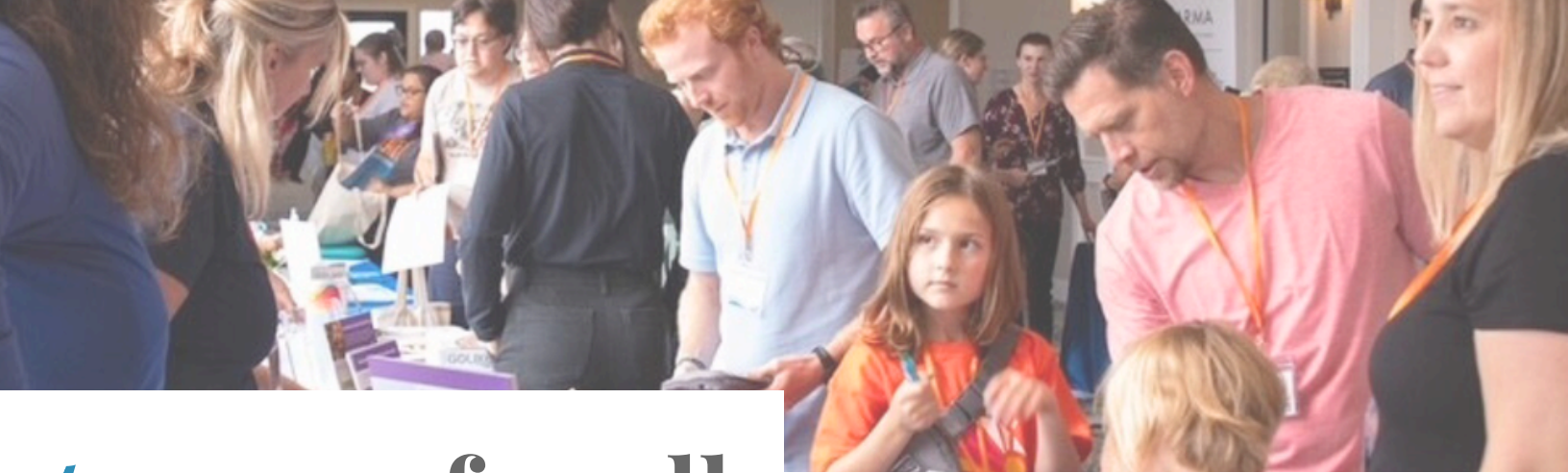


*“PKU-ers” Noah and Andrew*

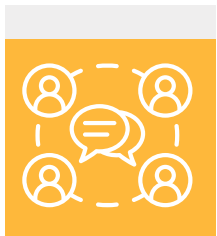
2025  
annual  
*progress* report

**NPKUA**  
national PKU alliance

*On a Mission to Cure. With a Passion to Thrive.*



# *progress* for all



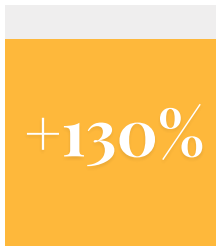
**180** attendees at the FIRST Regional NPKUA Conference



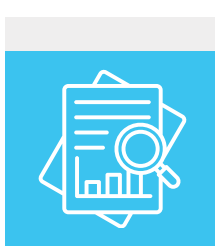
Cumulative NPKUA Home Phe Monitor investment, adding **\$250k** in 2025



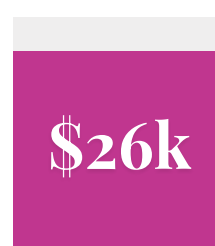
Supported **45** new mentees in the NPKUA Mentor Program



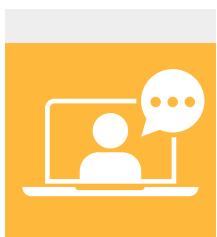
Increase in Move Your Pheet donations and registrations, raising **\$125,000** in 2025!



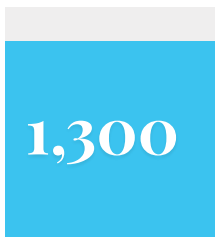
Awarded **5** PKU research grants totaling **\$425,000**



Funding for **6** NPKUA Affiliate community programs



Launched PKUniversity with **10 webinars**, 574 attendees and 3,000 views



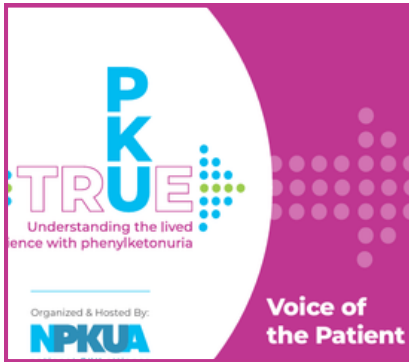
Views of the EL-PFDD meeting on YouTube, with **31 testimonials**



**206** support kits sent to PKU families with a newborn or kindergartner

And **350,000** social media views on PKU Awareness Day...empowering this community, educating others and amplifying progress and hope!

# Mission in *progress*



## Externally-Led Patient-Focused Drug Development Meeting and Report

Community members shared the daily impact, current management and treatment strategies and **what matters most** for new therapies in development. The FDA listened, alongside life science companies, health care professionals and researchers. **This is a lasting resource to represent the priorities of the PKU community and will guide everyone working to improve the lives of individuals with PKU.**

## Lifting the Limits for PKU

In New York City and San Diego, families and friends in our PKU community exceeded ALL expectations and raised a combined total of \$1.3 million for PKU research and support programs!

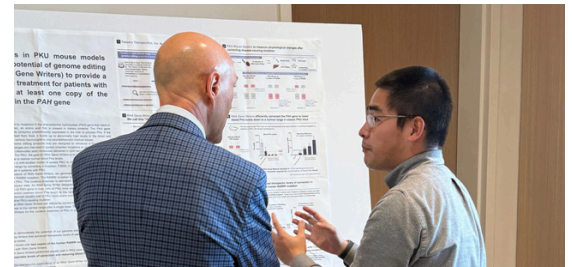


## Community Engagement

From dance parties and engaging panels at conference to hosting **virtual community calls for 250 attendees**, we created powerful moments of connection. NPKUA continues to champion support programs that educate (**kits, webinars and newsletters**), build relationships (**mentors and affiliates**) and drive change (**advocacy**).

## PKU Patient Registry

NPKUA upgraded the platform, strengthening the registry's ability to support PKU research. Registry participants grew to **1,130**, with **864** new survey submissions in 2025. The registry supported recruitment for **4 external research studies** and shared data in **its first scientific publication**.



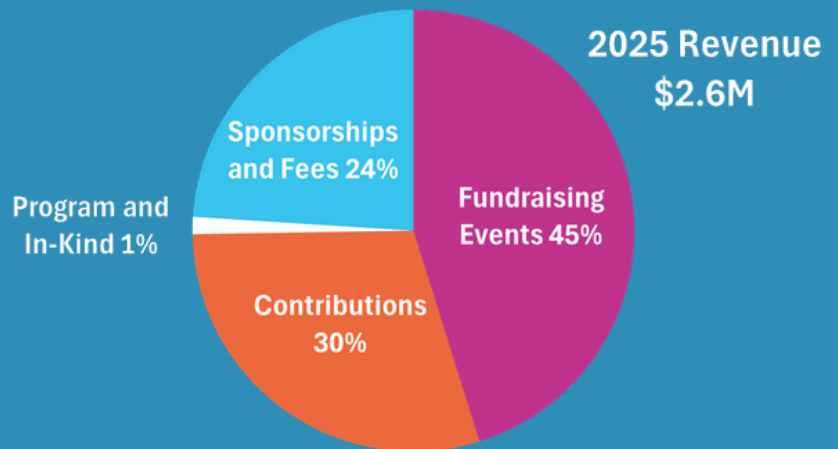
*“By giving, you're investing in both PKU research and PKU community programming, and that makes a real lasting difference for families like mine.”*

Melissa Goulart, NPKUA Mentor and adult living with PKU

# 2025 financial growth driving *PKU progress* today, tomorrow and years to come

8%

Revenue growth  
over 2024,  
increasing from  
\$2.4M to \$2.6M

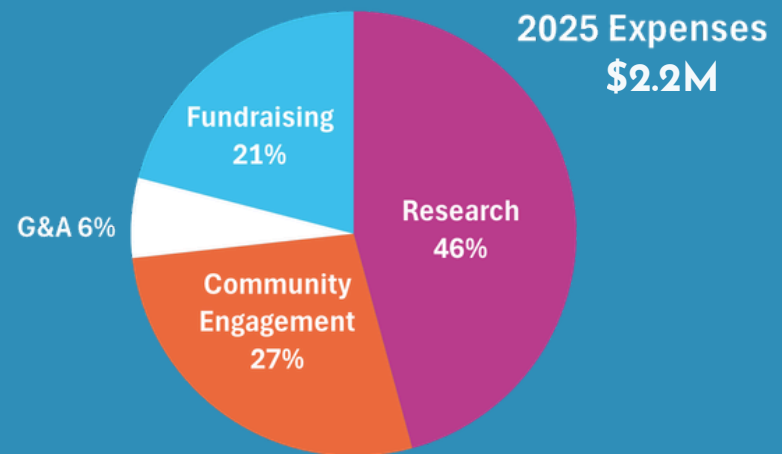


\$600k+

Dedicated to  
community  
support programs

\$1M+

Dedicated to  
research programs



73%

Program expense  
ratio

Net Income (excluding investment gains): \$383,298

Net Income (including investment gains): \$876,165



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