

NATIONAL PKU ALLIANCE 2022 IMPACT REPORT

15 YEARS OF PKU ADVANCEMENTS



TIMELINE

A look at where we have been since the NPKUA's formation

LOOKING FORWARD

What does the NPKUA have in store?

MEET

Learn about our newest NPKUA team members



npkua.org

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Executive Director



ALEXA BEICHLER

Staff – Operations



SUSIE GRAY

Director of Development



OLIVIA JONES

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ELAINA JURECKI

*Director of Research
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Genetics at Children's Hospital of
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in the Division of Genetics and
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**New Board Members*

MESSAGE FROM OUR EXECUTIVE DIRECTOR

As I reflect on the past 8 months, the magical moments have been the power of community, the importance of connection and the witnessed passion of our volunteers as well as our research, pharma, biotech, home-phe monitor, medical food and formula partner organizations. These vital partners are laser focused on providing products that make life with PKU better, and developing additional treatments, therapies, and ultimately a cure. The National PKU Alliance is lockstep with our partners as we continue our mission to improve the lives of all living with PKU while pursuing a cure.

As your Executive Director, I wanted to say thank you for the warm welcome, the outpouring of ideas and the willingness to volunteer, help build awareness, and the generosity of financial support which is critical for the NPKUA to thrive and grow. We have so much to be proud of. The accomplishments of the last 15 years are truly inspiring, and we expect the next 15 years will be pivotal and game-changing! Please take the time to review the 15 year milestones and our new and enhanced programs.

Our Neuro Cog Science Conference, newly formed Ambassador program, Patient Registry and the research grant process will continue to be robust and provide needed data to our stakeholders and funding for the advancement of treatments, therapies, and the path to the cure. We are committed to building a sustainable research strategic plan.

2023 will be a busy year, as we plan to redesign the NPKUA website, launch our NPKUA mentor program, For PKU, By PKU, a tailored support program, from connecting for a moment to connecting with a mentor; to actively and consistently engaging with our volunteers who are providing a much needed “extra set of hands.” The NPKUA will continue to fight for equity in medical foods and formula, and we will continue to support incredible local events, as well as our inspiring Lifting the Limit gala’s in Atlanta & Houston. Our partnership with the Nicklaus Children’s Healthcare Foundation continues with the golf event this summer, and we are proud to launch two new events in May to celebrate the importance of PKU Awareness Month with a National MOVE YOUR PHEET event and a 15th year Anniversary Celebration in NYC.

On behalf of the NPKUA Staff, Board, and myself, we are focused on keeping you current with information through our monthly newsletters, eblasts, and social posts. To quote Coretta Scott King “the greatness of a community is most accurately measured by the compassionate actions of it’s members” – our PKU community is strong and passionate, the NPKUA is here for each and everyone of you! We look forward to 2023 and continuing to build many additional milestones together!



Lisa Milberg
NPKUA Executive Director

2022 *a look at the* NUMBERS

\$700,000

funds raised during Creighton Farms Golf Invitational hosted by Jack Nicklaus in partnership with the Nicklaus Children's Healthcare Foundation

\$477,000

funds raised during the *Lifting the Limits for PKU* – San Francisco Bay Area event

384

attendees at the Challenging the Summit NPKUA Conference

129

members of the House and Senate signed on as MNEA cosponsors across the aisle

89

newborn kits sent in 2022

18

new YouTube videos uploaded including the debuts of our new Voices of Hope 2022 video and advocacy video on medically necessary nutrition

7

new NPKUA newsletters sent out to our entire audience

3

new grants provided to researchers

2

workshops led by our Advocacy Chair to empower grassroots efforts



TOGETHER
RAISED ALONE
NOW, TOGETHER,
ADVOCATES, CHAMPIONS
IN A BATTLE WE DIDN'T CHOOSE.
THE WORLD SEES "RARE"
WE SEE FRIENDS.

TOGETHER
WE DREAM
TOGETHER
WE FIGHT
TOGETHER
WE LIVE.



Kevin Alexander
PKU Adult

2022

Research Awards

The NPKUA awarded \$435,693 in grants in 2022 to:

Dr. Markus Grompe, MD, and their project entitled Cell Therapy for Phenylketonuria. The project will continue their previous development of a system that allows gene-edited hepatocytes to be selectively expanded in vivo by the administration of the drug acetaminophen. The next phase will use the transplantation of mouse hepatocytes to human hepatocytes in a humanized mouse model.

Dr. Gary O. Harding, MD, and their project entitled Novel Approaches to Achieving Permanent Gene Correction in PAH-Deficient Mice. The specific goals of the project are to improve the therapeutic effectiveness of 1) CRISPR/Cas9-facilitated gene correction of specific pathogenic Pah variants or alternatively 2) integration (gene insertion) of a phenylalanine hydroxylase (PAH) - expressing mini-gene containing the PAH cDNA into the hepatocyte genome of PAH-deficient mouse models of human PKU.

Dr. Susan Waisbren, Boston Children's Hospital, is evaluating the Cookie Theft Picture Task, a standardized instrument used to quantify verbal discourse (or spontaneous speech) in adults with PKU. The study aims to use machine learning to identify linguistic markers that differentiate adults with PKU from healthy adults without PKU. These markers may correlate with historical treatment and concurrent blood Phe levels. The study will also help to identify linguistic markers associated with other neuropsychological functioning and perceived severity and impact of PKU.

FROM 2010 TO 2022,
NPKUA HAS AWARDED
71 RESEARCH GRANTS
FOR A TOTAL OF
\$4.5 MILLION

Awards and Recognition

Alexa Beichler advocated for children and adults with PKU during the international formula shortage with several articles in *People Magazine* bringing PKU to the forefront and educating many about the impact it has on families. She also brought awareness for PKU with interviews with CNN, Fox News, and various other news outlets.

Dr. Sue Berry received the Clinician Champion Award by the Association of Public Health Laboratories (APHL) at its 2022 Newborn Screening Symposium. The Clinician Champion Award honors someone involved in patient care and who has made significant contributions to strengthen the impact of the public health newborn screening system by being directly involved in follow-up care, community affairs, newborn screening advocacy and/or community activities. Dr. Sue Berry serves on the NPKUA Board of Directors and is the Principal Investigator of the PKU Patient Registry.

Kala McWain secured Senator John Barrasso, MD as the first co-sponsor of the Medical Nutrition Equity (MNEA) Act in her home state of Wyoming. Kala was also featured on Today.com for her success and ongoing advocacy efforts to improve equity for her son and the future of metabolic and digestive communities in Wyoming. Kala is a member of the NPKUA's Advocacy Committee.

Amy Oliver received the RareVoice Award for Federal Advocacy by Patient Advocate or Organization by Every Life Foundation. After 10 years of ongoing advocacy work, Amy was able to urge the Federal government to change medical food coverage in the federal employee health benefit program for the treatment of PKU and other inborn errors of metabolism. Amy is the President and Founder of the Intermountain PKU and Allied Disorders Association, an NPKUA Affiliate. She also served as the President of the NPKUA Board for seven years, after serving for five years on the Board of Directors.

Claire Oliver and **Owen Maxfield** each received the RareVoice Award for Teen Advocacy by Every Life Foundation. Their successful advocacy work has led to every one of Utah's congress members to sign on as co-sponsors to the MNEA as well as to help their State Senator Kirk Cullimore introduce the Utah PKU formula program that ensures medical formula is available to all children in Utah.

Beginning in 2006, parents and grandparents form a working group to create National PKU Alliance (NPKUA), to unify the local and regional PKU and Allied Disorders groups throughout the USA.

PKU Cycle America, led by Founding Board Member Dick Michaux and his friend Jim Burger bike across the USA and raise \$175,000 and matched by BioMarin for a total of \$350,000 in initial funds to the NPKUA.

An NPKUA grant funds research by Denise Ney that leads to GMP usage in medical foods and formula supplement. GMP is the only real dietary protein that does not have phenylalanine in it. Cambrooke begins to integrate GMP into their products.

A second NPKUA grant for Denise Ney on bone health in PKU leads to additional funding from the Federal Drug Administration (FDA) for further clinical study.

Inaugural Conference, "High Hopes," Dallas, TX, 300 attendees.

Staff and Board members participate in five working groups at the National Institute of Health (NIH)'s Scientific Review Conference for PKU.

Funds research on genetically engineered probiotics that is later transferred to a biotech firm to develop a new treatment.

Second Conference, "Making History," Philadelphia, PA, over 500 attendees from 32 states and 9 countries.

NPKUA testifies before the FDA at a patient-focused drug development hearing.

Third Conference, "Reaching New Heights," Salt Lake City, UT, more than 500 attendees from 39 states and 8 countries.

2008

2010

2012

2014

2009

The Scientific Advisory Board is created to review and recommend research proposals for funding to accelerate PKU research.

Scott Pelley, then anchor of CBS Evening News, produces a public service announcement on PKU heard by 9.2M nationwide.

2011

Invests in cellular therapy that leads to the first US patient to receive a liver cell transplant as a possible cure for PKU.

32 NPKUA volunteers lead the fight for medical foods and coverage in Washington D.C. holding 60 meetings with congressional representatives.

2013

Partners to launch the InnoCentive world-wide Home Phe Monitor Challenge to create a device to check blood Phe levels at home.

Tuxes for Tia, Washington DC, \$1.6 million raised. A portion of the funds go towards winners of the Home Phe Monitor Challenge.

2015

Launches the Lifting the Limits for PKU Campaign to meet the need for continued research funding. Scott Pelley volunteers as the emcee for the first event and will go on to host 10 of Lifting the Limits to date.

Conducts its first national community survey to assess current health status and desire for new treatments that leads to a frequently cited publication in the journal of Molecular Genetics and Metabolism Reports 2016 vol 6 page 8-12.

First Lifting the Limits, Nashville, TN \$400,000 raised.

15 YEAR *Milestones*

Advocates at the national level with federal stakeholders at the NIH and FDA for better treatments for PKU.

Fourth Conference, "Taking the Lead for PKU" Indianapolis, Indiana, 605 attendees from 35 states and 7 countries, becoming the largest gathering in the world for PKU individuals.

Lifting the Limits, Boston, MA \$400,000 raised.

Lifting the Limits, Seattle, WA \$500,000 raised.

2016

Brings together officials from the FDA, industry, neuropsychologists and PKU clinicians to discuss regulatory agreements during the clinical trial process for PKU drug development.

Fifth Conference, "Advancing the Dream," Atlanta, Georgia, 665 attendees from 34 states and 8 countries.

Lifting the Limits, Denver, CO \$400,000 raised.

Lifting the Limits, New York, NY \$600,000 raised.

Creighton Farms Invitational Hosted by Jack Nicklaus, \$505,000 raised.

2018

Crossing Norway for a Cure, spearheaded by Alison Reynolds, who completes her cross country ski of 125 miles across Norway over nine days to raise \$1.07 million for PKU research.

Launches the Affiliate Council to bring together local and regional PKU organizations to support Affiliates and individuals with PKU.

Sixth Conference Virtual PKU series, "A Little Different, A Lot Awesome," 568 attendees.

Creighton Farms Invitational Hosted by Jack Nicklaus virtual fundraiser, \$10,000 raised.

2020

Sponsors a pilot genetic testing program to increase community access to testing and enhance the collection of genomic data in the PKU Patient Registry.

Seventh Conference, "Challenging the Summit" Vancouver, WA 384 attendees.

Lifting the Limits San Francisco, CA \$477,000 raised.

Creighton Farms Invitational Hosted by Jack Nicklaus, \$700,000 raised.

2022

Collaborates with BioMarin and the FDA to provide patient testimony to support the approval of Palynziq. Palynziq is the first and only novel enzyme therapy that exists for PKU treatment today.

Launches the PKU Patient Registry to accelerate research, enrolling 550 participants including 41 states and 5 countries in the first year.

Lifting the Limits, Buffalo, NY \$80,000 raised.

Creighton Farms Invitational Hosted by Jack Nicklaus, \$500,000 raised.

2017

Forms partnership with PHEFREE Consortium to support the two NIH studies currently underway. NPKUA participates in two virtual meetings associated with this group.

Lifting the Limits, Philadelphia, PA \$260,000 raised.

Creighton Farms Invitational Hosted by Jack Nicklaus, \$400,000 raised.

2019

Launches the NPKUA Mentor Program to provide individualized assistance to PKU adults.

Lifting the Limits, Breaking Boundaries, Virtual Event, \$278,000 raised.

Creighton Farms Invitational Hosted by Jack Nicklaus, \$565,000 raised.

2021

Established in 2008, the NPKUA's initial Board was comprised of nine members. Today, the NPKUA has grown to an eight member staff, 14 Board members, and 12 Affiliate organizations and counting.

2023



NPKUA 2023

peek into the future

RESEARCH & PATH TO A CURE

With Elaina Jurecki, Director of Research Development, at the helm, we are refining our scientific research strategy to align with the current development landscape of new potential treatments and therapies. We have set up a cadence of monthly calls and updates with our industry partners and Home Phe Monitor partners to collaborate more effectively and efficiently together.

We are really excited for our first, multidisciplinary NPKUA science conference **“Break free from Phe” neurocognitive conference** which will be held in Denver, CO from April 20-22, 2023, where the leading scientists, researchers, and clinicians will have the opportunity to collaborate on their PKU research and critical endpoints to PKU clinical trials. We have had a tremendous response from industry and our PKU research and clinical community, and we can't wait to provide the PKU community with an update after the conference!

Our request for proposals for our 2023 Research grants is out with a May 1st deadline for submission and we are eager to see and review the requests with our **Scientific Advisory Board** in conjunction with our **Scientific Advisory Council**. It is always an exciting time when we get a glimpse into what academia, researchers and

neurocognitive professionals have identified and are working on!

We are often asked by our pharma, industry, and regulatory partners for feedback from PKU individuals and families. To streamline this process, we have created our **NPKUA Ambassador Program** to respond to these requests as they come in to help our industry partners better understand the needs of individuals with PKU, their families, and our community. If you are interested in participating in an advisory council for a pharma company or, a focus group, please let Alexa@npkua.org know of your interest.

To further the connection between our PKU community and our industry partners, we launched the **NPKUA Networker Newsletter this February** to offer a platform for each of our Pharma & Biotech industry/medical foods & formula/Home Phe Monitors an opportunity to share recent developments, product announcements, clinical trials and anything critical to our PKU Community. We plan to run a second series of the Networker Newsletter in August 2023 to provide further developments from our partners.

COMMUNITY ENGAGEMENT & COMMUNICATION

After gathering feedback from our mentors and learning about the needs of our new mentees, we are excited to launch our **NPKUA Mentor Program, For PKU, By PKU A Tailored Support Program, From Connecting for a Moment to Connecting with a Mentor**. This program will now incorporate our three previous programs PEER, PATHWAYS, and Maternal into one and is designed to be more collaborative and flexible to the mentee's needs. Our **New Volunteers Group** is up and running with 85 current members. Our productive conversations are

aimed at providing the new volunteers an overview of the NPKUA, our upcoming events and where we may need further assistance. It is also a time for volunteers to meet each other and learn about the talented skills each of them can bring to the table. We are excited to continue to engage with this group to consistently hear from our PKU community what is needed at that moment and for the future and to share ideas, and to connect our community. We meet quarterly at 8pm eastern and if you are interested, please reach out to Alexa@npkua.org.

We are working to provide, **PKU Talks**, in 2023, an online library of recorded webinars, moderated panels and videos from the NPKUA that will cover a myriad of topics of interest to our PKU community. Whether you can join us on the scheduled day of the webinar, or would like to share with your friends, we want our content to be accessible for our community at any time.

The NPKUA, through its existing grassroots **Advocacy Committee**, co-chaired by Lillian Isabella and Jackee Austerman, will continue to guide our community and work with key stakeholders to keep MNEA, and other state and federal legislation top of mind. Together with our **Affiliates Council**, co-chaired by Heidi Maxfield and Heather Bomar, we keep our affiliates and smaller

networks connected with a monthly Affiliate newsletter, social posts for the affiliates to share and quarterly meetings to share best practices and discuss priorities.

I am thrilled to be witnessing the connections that are being made in the PKU community. Working together and creating more awareness of PKU is a large factor to this and it is exciting to be apart of. There is a great future for the PKU community and I cannot wait to see it all!

Maridith Baker
PKU Young Adult

Our NPKUA staff is working with our **Communications Committee** on revamping our NPKUA website for easier navigation and to provide the information you need in a simplified, easy manner that will connect the PKU community to their particular need at the moment. Stay tuned for updates along the way!

Lastly, we will continue to provide a quarterly **NPKUA**

Newsletter, eblasts when critical information is relayed to us and social posts to keep the PKU community abreast of current information and to ensure that our voice is consistently heard.

2023 NPKUA FUNDRAISING EVENTS

Our **Fundraising Committee**, chaired by Alison Reynolds, will bring a handful of in-person events in 2023 including our **15th year anniversary cocktail party** celebration in New York City on May 16th; a national event during PKU Awareness Month – **“Move your Pheet”**; two **Lifting the Limits Galas** in Atlanta (Sept 23) and Houston (Nov 11), the Creighton Farms Golf Invitational in August, and we are in planning stages for a Research Dinner in late Fall of 2023.

For 2024, we are in the planning stages of three Lifting the Limits galas, and our Annual NPKUA Family conference for July of 2024! If you are interested in being a Co-Chair for a Lifting the Limits gala, please let Blair@npkua.org know!

In addition to the NPKUA sponsored events, there are a myriad of fundraisers that are sponsored by individuals in our PKU community to raise much needed funds – to all of you, THANK YOU!

2023

save the dates

APRIL

20/22 – PKU Break Free from Phe Conference in Denver, CO

MAY

PKU Awareness Month and Move Your Pheet Virtual Race
16 – 15th Year Anniversary NYC Cocktail Reception

JULY

Climb to Cure PKU

AUGUST

27/28 – Creighton Farms Invitational Hosted by Jack Nicklaus

SEPTEMBER

23 – Lifting the Limits for PKU Gala Atlanta

NOVEMBER

11 – Lifting the Limits for PKU Gala Houston

DECEMBER

3 – PKU Awareness Day

2024

JULY - Annual Conference

For more on upcoming NPKUA events, contact Blair@npkua.com



NPKUA PATIENT REGISTRY *Update*

Over the last year, NPKUA received requests from academic investigators and life science companies on a weekly basis who were looking for support from the PKU Patient Registry. They recognize our value as a network of research-ready participants who are passionate about doing their part to advance PKU research. In 2022 advanced PKU research brought the patient voice to clinicians and researchers around the globe by:

- Supporting recruitment for 13 academic and industry research studies.
- Sharing data to support product development.
- Reviewing and updating our medical history surveys and genetics surveys to facilitate data sharing with NIH natural history studies and databases.
- Launching a Genetic Testing Program to increase community access to testing and enhance the collection of genetic data.
- Presenting at: NPKUA's Neurocognitive meeting (Jan 7), NIH Rare Disease Day (Feb 28), GMDI/SIMD (May 4), NPKUA Conference (July 8), NORD Summit (Oct 16), and NORD's IAMRARE Registry Leadership Meeting (Oct 19).



The NPKUA has been avidly working towards advancing the science of PKU to support development of new treatment and management strategies and ultimately a cure to improve the lives of individuals with PKU. To support these efforts, we have met with many clinicians and industry representatives to provide support with conducting research through funding and recruitment efforts as well as with providing guidance on study design. This is a very exciting time for PKU as the landscape of ongoing research has grown tremendously with well over 20 companies planning or conducting studies in PKU.

Elaina Jwzecki
NPKUA Director of
Research Development



To continue to grow the NPKUA's biggest asset, we have ambitious plans for 2023!

- Explore models to expand our database, including collaborations with academic researchers and industry sponsors to collect new data and “inherit” external PKU datasets from other sources.
- Partner with academic investigators, industry, regulators and the PKU Community to integrate the patient perspective as measures to evaluate the benefits of new treatments and success of medical care.
- Find ways to better engage the PKU community. The more people who support this initiative by enrolling in the Registry and donating their health data, the bigger the impact we can have on PKU research and care.

To accomplish all these priorities, we need ***your*** help. Our Registry efforts would not be possible without the ongoing support of our amazing Registry participants. Whether you are already a proud supporter of the Registry or are interested in learning more about this impactful initiative, **please visit pku.iamrare.org, and together, we can improve the future of PKU!**

PKU AWARENESS MONTH

1. *Move Your Pheet*

This May, we are celebrating NPKUA's 15th year anniversary and National PKU Awareness month. Move Your Pheet will be a nationwide virtual fundraising event that can take place anytime during the month of May. Move Your Pheet can be any type of exercise or movement you like – just as long as you move your feet! NPKUA will be providing tools to promote and manage your own event, whether it's a town run, a walk around the neighborhood that includes dogs and strollers, a bike ride, or a night glow walk/run.

These individual community fundraisers are designed to bring awareness to PKU and raise funds for NPKUA's For PKU, By PKU Mentor program. It's the perfect way for friends, families, neighbors and colleagues to unite to support our mentors. All while having fun and promoting physical health, which is so important to our PKU community. It's a win-win!

Stay tuned as NPKUA will be rolling out the Move Your Pheet fundraising program. Contact Blair@npkua.org to join the effort!

Move Your Pheet!



2. *Light up the Night*

Celebrating National PKU Awareness month and the 15th Anniversary of the National PKU Alliance

Light Up the Night for a Cure

Tuesday, May 16 • 6:30 - 9:30 PM
The Lighthouse, Pier 61 at Chelsea Piers
New York, NY 10011

Catered by Abigail Kirsch

Join us in New York City, on May 16th to celebrate the 15th year anniversary of the NPKUA, an evening of cocktails, heavy hors d'oeuvres, brief NPKUA programming, inspiration and fun.



GET TICKETS!



NPKUA
IS GETTING A
NEW WEBSITE!

DECEMBER 2023

NATIONAL PKU ALLIANCE

954 Lexington Avenue #269

New York, NY 10021 United States

THE NPKUA'S MISSION IS TO IMPROVE THE LIVES OF INDIVIDUALS WITH PKU AND PURSUE A CURE.



2022 was an active year for the PKU Community and as a member of the NPKUA Advocacy Committee, I was so encouraged to see so many new faces getting involved! Many individuals have put forth their best efforts with spreading PKU Awareness, reaching out to Congress about the MNEA and showing up for families when the formula shortage hit hard. It is an exciting time to see these new PKU families coming alongside adults with PKU and some of us 'veteran' PKU parents. This makes me believe we can do really great things in the coming year for our PKU Community and beyond!



Jackee Austerman
PKU Caregiver

For our new moms, please let us know if you have not received an NPKUA newborn kit, filled with information & products for you and your newborn!



Reach out to alexa@npkua.org for your kit.

npkua.org | 715.495.4008

