



## About Us

### Our History

Georgia PKU Connect was founded in 2008 by three mothers, each with a child born with Phenylketonuria (PKU). Support for the organization was cultivated through an online, Georgia focused PKU discussion group and the inspirational spirit of Emory University's Metabolic Nutrition Team. The successful launch of Georgia PKU Connect can also be attributed to the positive energy and contributions of local families and adults with PKU!

### What is PKU?

PKU is a rare, inherited metabolic disorder. If left untreated, PKU causes devastating neurocognitive and psychiatric problems, including severe intellectual disability when treatment is not started within the first few weeks of life. Newborn screening for PKU began in 1963, and became a mandatory national public health program in 2007. Unfortunately, a majority of teens and adults struggle to maintain treatment due to the complexity and expense of maintaining a strict medical food diet. To prevent disability, the treatment must be continued for life.

### Our Mission

To connect PKU families and individuals with the support and resources they need to manage PKU and live healthy, productive lives.

### Board of Directors

#### Shiela Cochran Ryan, RDN, LD, President

Shiela Ryan has been a member of the Georgia PKU Connect Board of Directors since 2009. She graduated in May 2017 from the Georgia State University Undergraduate Program (DPD) in Nutrition and Dietetics and completed her dietetic internship in the fall of 2017 with Keith & Associates Dietetic Distance Internship (KADDI). Shiela also holds a Bachelor of Business Administration with a focus in Human Resources Management from Columbus State University. Prior to studying Nutrition at GSU Shiela held a management position in Employee Benefits for Synovus Financial Corp. for over 10 years. While not studying nutrition or connecting with Georgia PKU families Shiela enjoys spending time with her family, running, and cooking. Her interest in supporting the PKU community began with the diagnosis of her Nephew in 2008 and her professional journey in nutrition continues with her role as an outpatient dietitian working for Morrison Healthcare at Wellstar in Atlanta, Georgia.

### **Kristen Vanags, Vice-President, Advocacy**

Kristen Vanags is a co-founder and former president of Georgia PKU Connect and a leading advocate for medical foods coverage. She also serves on the Georgia Newborn Screening Advisory Committee and the National PKU Alliance Affiliate Council. Kristen is a trusted expert on medical nutrition legislation and has lead advocacy initiatives at the state and federal level for over 10 years. Kristen previously served on the board of the Southeast Regional Genetics Group and was the chair of the Southeast Newborn Screening & Genetics Collaborative Consumer Alliance. Kristen received the inaugural Applied Nutrition ROSE Award and coordinated the first National PKU Awareness Day with U.S. Senator Johnny Isakson (GA). Prior to her engagement in non-profit work, Kristen was a business process consultant with Accenture and later did freelance change management consulting. Kristen lives with her husband and two children in Atlanta, home of her alma mater, Georgia Tech.

### **Christina Gang, Treasurer**

Christina serves as Treasurer on the Board. Christina is originally from Philadelphia, PA and moved to Atlanta, GA with her two children, in 2011. Having moved to a new city, Christina wanted to connect with other families who live with PKU and found Georgia PKU Connect via a Google Search and connected with Kristen through the “Connect with Us” link on the website. Through Georgia PKU Connect’s annual Camp Connect, Christina’s daughter Elizabeth learned the importance of maintaining her diet and most importantly that she is not alone. In 2018, Christina was asked to join the Georgia PKU Connect, Board of Directors as Treasurer. Professionally, Christina has held various roles within the Finance & Accounting organization at Turner Broadcasting, since 2011. She is currently supporting CNN’s Digital businesses as Manager of Financial Analysis. Christina graduated from Temple University with a B.B.A. in Accounting and has passed all four parts of the CPA exams. She currently lives in Atlanta, with her son Daniel and Elizabeth.

### **John Lorimer, Secretary**

As the parent of two PKU adults, John has been actively involved in PKU issues for several decades, including serving as President of the Illinois PKU Parents Organization in the past. Professionally John worked in the fields of Communications, Technology, Human Resources and Risk Management, and was Vice President of Analytics Product Management for LexisNexis, specializing in fraud mitigation. John is now a consultant and Vice President of Analytics for iParametrics. He also spends much of his time volunteering with several charitable organizations, including assisting with Georgia PKU Connect.

### **Cathy Lorimer, At Large**

Cathy is a mom of two PKU adults (and one non-PKU child) born in the early days when the PKU Collaborative Study was still determining how long children should remain on diet. A native of Illinois, Cathy retired with her husband and is currently living in Georgia. Cathy served on the Illinois PKU board for two consecutive terms. She was responsible for layout and design for the quarterly PKU Press of Illinois, and helped with the annual Illinois PKU conferences. Finding few resources for managing the diet, Cathy wrote and published the “Low Protein Cuisine”

cookbook in 1991 after her niece was also born with PKU. Eventually, with the advent of the internet, Cathy designed and served as webmaster for the first Illinois PKU website. Though her children are now grown, being educated and helping in the PKU world is important to her. Her PKU son and his wife are now living nearby in Georgia, and her PKU daughter lives in Illinois with her husband where she regularly speaks and writes on behalf of PKU.

### **Daniel Almeida, At Large**

Daniel Almeida is a senior financial executive, with 20 years of experience in investment and risk management, insurance and derivatives. After many roles within ING Group and Aflac in Brazil, Latin America and USA, he is now the Director for Global Risk Management at Intercontinental Exchange Inc. When his younger daughter was diagnosed with PKU in 2008, he met Kristen via the Emory Genetics Clinic and they have been in contact since then. Given his personal link to the PKU community and also professional background, in 2015 he was invited to join the Board of Georgia PKU Connect. Besides supporting all its activities, his main focus in the group has been on Organization Planning and Board development, determining skills, experience needed, and defining board member roles and responsibilities. Daniel lives in Atlanta with his wife and 2 daughters.

### **Lindsey Coltraine, At Large**

Lindsey Coltraine is a Registered Nurse who works in pediatrics, and she is a Family Therapist where she works with couples and adult individuals. She graduated from the University of Georgia with a Bachelor of Science in Psychology before going on to complete her Masters of Nursing degree with Georgia Health Sciences University and Master's in Family Therapy degree with Mercer University. She is married to Brian Coltraine, and they have a son who was born in October 2015 with PKU. They also have another son who was born in September 2019. Lindsey has been very active in the PKU community and is proud to serve on the board. Her passion is connecting with new families and helping to ease the transition into the PKU world.

### **Erica Shaddix, At Large**

Erica Shaddix has been a member of Georgia PKU Connect since June 2011 when her daughter, Emily, was diagnosed with PKU. Erica earned both undergraduate and master's degrees from Georgia State University in Early Childhood Education. She is a Certified Teacher in the State of Georgia for Pre-K through 5th grade and has taught in various classroom settings. Erica is currently the Director of a private preschool in the Atlanta area, where she lives with her husband and two daughters.

## **Committees**

### **Outreach and Support**

The Outreach and Support Committee creates opportunities to connect PKU community members with the organization, and members to members. This committee also provides educational resources and community activities to promote a holistic supportive environment. In addition to PKU community members, the Outreach and Support Committee welcomes

individuals affected by other inherited metabolic disorders to connect with us, so we can communicate activities and events that may be of interest beyond PKU.

Examples of outreach and support include new patient welcome packets, reaching out to new community members, answering questions, resource navigation, community building social activities, and educational workshops.

### **Advocacy**

Although the law requires every state to screen newborns for PKU, there is not adequate coverage for the required treatment. The Advocacy Committee raises awareness for this issue and promotes solutions to ensure affected children and adults have access to the medical nutrition required to treat the disorder. By treating PKU throughout the lifespan, diagnosed babies have the opportunity to be healthy and stay healthy.

Examples of advocacy include development and support of state and federal legislation providing equitable insurance coverage of medical nutrition, promotion of state funded assistance programs, and educating caregivers about the use of 504 plans in public schools.

### **Camp Connect**

Each year, Georgia PKU Connect holds a weekend family support camp in partnership with the non-profit Camp Twin Lakes (CTL). CTL provides year-round, full-accessible, and intentionally designed camps that teach campers to overcome obstacles while creating shared experiences with other children who face similar challenges. The Camp Connect Committee collaborates with CTL to plan and organize our PKU camp program, which serves over 100 PKU family members for three fun-filled days during the month of September. PKU safe meals are provided and life-changing friendships are made. PKU adult volunteers also play an important role by helping activities run smoothly and by providing encouragement to our campers. Camp Connect is open to PKU families in Georgia, as well as other states.

### **Fundraising**

The Fundraising Committee is primarily focused on identifying, developing and implementing fundraising opportunities to support Georgia PKU Connect's mission. Committee members work closely with the executive committee to identify the financial needs of the organization and develop the governance model for allocating funds.

Examples of fundraising activities include the annual Camp Twin Lakes Spin for Kids bike ride, PKU Awareness events, Facebook fundraisers, school and neighborhood events, applying for grants, planned giving, and requesting corporate donations.

## **Georgia PKU Connect and the National PKU Alliance**

In addition to our work supporting the local PKU community, Georgia PKU Connect actively participates in the activities of the National PKU Alliance (NPKUA). These activities include monitoring and supporting the NPKUA's research efforts for better treatments and a cure,

playing a key role in national advocacy efforts, and participating in the NPKUA's Affiliate Council to identify and promote opportunities to improve PKU lives across the United States. We encourage all members of our community to stay connected with the National PKU Alliance by signing up for their mailing list at <https://www.npkua.org/#signup>.

## **Staying Connected to Georgia PKU Connect**

Please connect with us! To join our mailing list, or to update your contact information, visit <https://georgiapku.org/contact/> to complete our quick "Get Connected" form.

If you have any questions or comments for our organization, please email us at [info@georgiapku.org](mailto:info@georgiapku.org) – we would love to hear from you!