

National PKU Alliance, Inc.  
Research. Education. Support. Advocacy

**Help Us  
Create the  
Future of PKU**

# Announcing the Formation of the National PKU Alliance

There is great news within the PKU community! The first national PKU organization has been formed – the National PKU Alliance (NPKUA). NPKUA's mission is to improve the lives of individuals and families associated with PKU through research, education, support and advocacy, while ultimately seeking a cure. This vision is the result of an effort over the past nine months by 53 PKU family members operating as a charter organization. Bringing together the grass roots efforts of 20 local PKU organizations, 100 metabolic clinics, national and worldwide researchers, pharmaceutical companies and PKU vendors will provide a focus on national issues where a unified approach will leverage the capabilities of all these organizations.

**How you  
can  
help**

NPKUA is seeking donations to help fund the first two years operations, budgeted at \$375,000. This budget includes funding for advocacy, awareness and education programs that will be run by a professional Executive Director. Please consider making a donation of any size to enable the vision and to start the important work of NPKUA.

Thank you for supporting NPKUA!

**Send your tax  
deductible donations  
to:**

Michaux Family Foundation  
10332 Main Street, #358  
Fairfax, VA 22030

If you have any questions about NPKUA, please contact:

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## **What NPKUA means to the PKU**

### **Community:**

- NPKUA is an alliance of local PKU organizations that will seek to include everyone who shares the desire to create the future of PKU
- NPKUA will form a Research Development and Review Committee to review PKU research proposals and recommend for funding those with the best potential to find real solutions to PKU issues
- NPKUA will advocate locally and nationally for legislative and insurance changes to enhance coverage for PKU treatments
- NPKUA will exchange best practices for a) treatment protocols among metabolic clinics and b) fundraising and educational campaigns among local organizations
- NPKUA will sponsor national and international conferences for all who have an interest in PKU issues