



**New England Connection for PKU and Allied Disorders**  
**A Non-Profit Organization**  
**27 Murray Circle in Raynham, MA 02767**  
**[www.necpad.org](http://www.necpad.org)**

**IMPORTANT INFORMATION ABOUT FINANCIAL ASSISTANCE  
FOR MASSACHUSETTS PKU PATIENTS AND THEIR FAMILIES**  
**\*\*\*PLEASE READ CAREFULLY AND ACT NOW\*\*\***

January 2021

Dear Massachusetts PKU and Allied Disorder patients and families:

**The New England Connection for PKU and Allied Disorders (NECPAD) has some wonderful news about financial assistance that is available for Massachusetts PKU and Allied Disorder patients and their families!** A Massachusetts Fiscal Year 2021 appropriation in the amount of \$50,000 was passed, once again, with the help of Rep. Christine Canavan, a longtime supporter of the PKU/AD community, and now a PKU grandmother! NECPAD has been charged with the responsibility of disbursing these funds to MA PKU/AD families following a budget that was submitted to and approved by the MA Department of Public Health (DPH). Please see attached Frequently Asked Questions to learn more about NECPAD and the Canavan Grant.

**The Canavan Grant began in January 2021 and will expire as of June 30, 2021. NECPAD may only consider requests for reimbursement of purchases and expenses incurred between those dates.** The budget allots funds for the support of MA PKU/AD patients and their families in a broad range of categories. Patients and family members may request funding in the following categories:

1. Medical Supplies
  - a. Scales
  - b. Low Protein Cookbooks
  - c. Low Protein Food List
  - d. Small appliances for use in low protein food preparation
  - e. Containers, mini fridges or freezers for use in formula or low protein preservation
2. Medical Foods and Formula
  - a. Low Protein Food (not otherwise covered by insurance)
  - b. Medically Prescribed Formula (not otherwise covered by insurance)
3. PKU Events
  - a. Face Forward Program (must be registered and paid for by June 30, 2021)
  - b. SSYMCA Camp on Cape Cod or other camp (must be registered and paid for by June 30, 2021 but camp can occur after June 30th)
  - c. Apple Picking, Kimball Farms and Conference
4. Clinic Support/Services (reimbursement for costs associated with clinic appointments)
  - a. Parking fees
  - b. Transportation to/from clinic
  - c. Reimbursement for Deductibles/Co-pays
5. Scholarships for PKU patients in college\* level or greater courses \*some exceptions may apply

**Please complete the attached application to apply for funds from the Canavan Grant.** Again, please note that the Canavan Grant is only for PKU and Allied Disorder patients residing in Massachusetts for expenses incurred between January 2021 and June 30, 2021. Attach receipts and/or supporting documentation where required and submit to NECPAD **no later than June 1, 2021** to the following email [necpad.org@gmail.com](mailto:necpad.org@gmail.com) or address:

**NECPAD**  
**Attn: Canavan Grant**  
**27 Murray Circle**  
**Raynham, MA 02767**

**\*Late applications accepted but all applications processed on “first come, first served” basis!**

Thank you for your attention to this important and *time sensitive* opportunity.

*All our best,*  
**NECPAD Board of Directors**



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**FREQUENTLY ASKED QUESTIONS  
ABOUT NECPAD AND THE CANAVAN GRANT**

February 2021

**What is NECPAD?**

The New England Connection for PKU and Allied Disorders, Inc. (NECPAD) is a 501 c 3 nonprofit organization which is committed to fulfill its working mission to inspire learning, social support, research and public policy to help develop the full potential of people affected by PKU and Allied Disorders (AD). We are proud to support those living with PKU, their families and professionals throughout New England. Our Board of Directors comes from across New England and is comprised of patients, parents and clinicians who all dedicate their time and energy to support NECPAD's mission.

**What is the Canavan Grant and how can it help Massachusetts PKU patients and their families?**

Thanks to the hard work and dedication of retired Representative Christine Canavan, proud PKU grandmother, and the support of the NECPAD community, we were able to pass a Massachusetts Fiscal Year 2020 appropriation in the amount of \$50,000 – this is the sixth such appropriation since 2009! In honor of Representative Canavan, NECPAD has respectfully renamed this funding the “**Canavan Grant**”! The Canavan Grant will support the costs associated with a budget that NECPAD has proposed to the MA Department of Public Health (DPH) that oversees the allocation of these funds. NECPAD is responsible for disbursing these funds in accordance with this budget. **PLEASE NOTE: The Canavan Grant began on January 2021 and will expire as of June 30, 2021.** NECPAD may only consider requests for **reimbursement or new purchases for expenses incurred between those dates.** The budget allots funds for the support of PKU and Allied Disorder patients and their families in terms of the following categories.

1. Assistance for new families and/or those in need
  - a. Low Protein Food Lists
  - b. Gram Scales
  - c. Transportation to clinic or family meetings
  - d. Low Protein Food Samples
  - e. PKU.com or GO LOW PRO subscriptions
  - f. Parking vouchers
  - g. Deductibles/co-pays
  - h. Small appliances
  - i. Larger appliances
2. PKU School/Cooking Demonstrations
3. Low Protein Food (not otherwise covered by insurance)
4. Medically Prescribed Formula (not otherwise covered by insurance)
5. Face Forward program
6. PKU Camp and the YMCA on Cape Cod or other camps
7. Family Support Events – NECPAD
8. Scholarships
9. Other expenses in administering the grant (e.g. postage)

**Does NECPAD have any plans to expend part of the Canavan Grant to help educate families and bring them together to support each other?**

We hope to organize a Conference and Family Fun Event after COVID ends.

## **How will the Canavan Grant be expended this Fiscal Year?**

We now have our work cut out for us to ensure we fully expend the Canavan Grant to directly benefit Massachusetts PKU/AD patients and their families. NECPAD is proud to be able to administer the Canavan Grant this year. Because of the June 30, 2021 deadline for the Canavan Grant, NECPAD needs to move quickly to ensure the funds are fully expended. NECPAD has sent out applications via the metabolic clinics, the PKU listserv and by e-mail in an effort to invite all MA PKU/AD patients and their families to apply for assistance.

## **How do I apply for Canavan Grant funds?**

Please see the attached application for how you can apply for the Canavan Grant. Again, please note that the Canavan Grant is only for PKU/AD patients and their families residing in Massachusetts for expenses incurred between January 2021 and June 30, 2021 (NOTE: The Canavan Grant can include the SSYMCA Camp and Face Forward program as long as PKU/AD patients are registered and paid for on or before June 30, 2021. NECPAD can pay tuitions directly as long as individuals are registered, or NECPAD can reimburse patients AS LONG AS THE TUITIONS ARE PAID FOR ON OR BEFORE JUNE 30, 2021.)

**Please read the application carefully, follow the directions, complete it in its entirety, and return the application and any receipts or supporting documentation to either [necpad.org@gmail.com](mailto:necpad.org@gmail.com) or send to the following address:**

**NECPAD – Canavan Grant  
c/o Tanya Parrazzo  
27 Murray Circle  
Raynham, MA 02767**

***APPLICATION DEADLINE IS JUNE 1, 2021.  
Late applications, up until June 30, 2021, will be accepted.  
PLEASE NOTE: All applications will be reviewed and  
processed on a “first come, first served” basis.***

## **Will I automatically receive assistance from the Canavan Grant if I apply?**

NECPAD will do its best to accommodate every request for assistance as possible given the budget that has been approved by DPH, but we cannot guarantee that all requests will be granted. NECPAD will work closely with the metabolic clinics to reach out to all Massachusetts PKU/AD patients and their families and to determine need.

## **How do I learn more about the Canavan Grant?**

If you have any questions when completing the application or about the Canavan Grant in general, please e-mail [necpad.org@gmail.com](mailto:necpad.org@gmail.com) or call Denise Queally at 781-706-9219.

## **Who currently serves on NECPAD and how can I become more involved?**

NECPAD is a dedicated, nonprofit organization. It welcomes future Board Members to fulfill its working mission to inspire learning, social support, research and public policy to help develop the full potential of people affected by PKU and Allied Disorders. **WE NEED YOU!**

NECPAD will gather contact information from the applications submitted. We will use this to add to or update our current mailing list. When you receive notifications of upcoming events, this is your open invitation to join other families for support and fun.

***Thank you!  
NECPAD Board of Directors***

*To learn more about NECPAD, please visit our website [www.necpad.org](http://www.necpad.org).*