














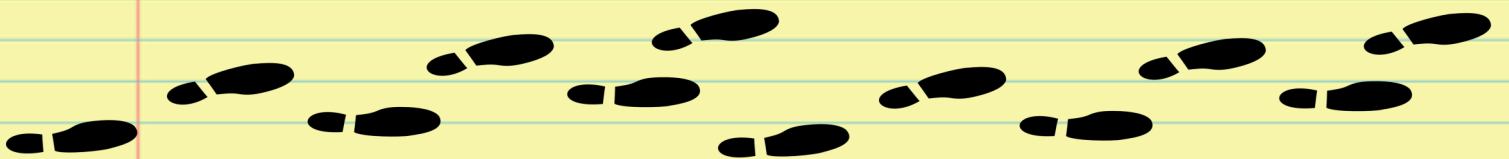
Fall 2017

PKU Press



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NPKUA Update: Medical Nutrition Equity Act

By Kim Kowalczyk

This past May, we had the honor of traveling to Washington D.C. with the National PKU Alliance to lobby in favor of the Medical Nutrition Equity Act. This bill would require all private and federal health insurance plans to cover medical formula, foods, and nutrition for patients with in-born errors of metabolism including PKU.

Before heading to D.C., we worked really hard reading up on legislation, calling and writing to our congressmen, and reaching out to our PKU community to help us contact their own congressman. There were many late nights, filled with coffee and snacks, but all the preparation was worth the outcome in the end.



We arrived in Washington D.C. with the MNEA as a draft bill with bipartisan support in the Senate and only democratic support in the House. Together, we completed 108 meetings in a 36 hour time frame and made a TON of progress! By the end of our trip, we had bipartisan support from both congressional parties, with multiple co-sponsors, and have introduced our bill to the financial committee in order to get an estimated cost of our bill.

On a more personal note, I think the biggest impact this experience had on me was understanding how valuable



even just a 20 minute meeting with our congressmen is in terms of making a legislative change. I was pleasantly surprised by how eager our congressmen were to learn. They were so interested in what we had to say, and wanted to understand PKU and the struggles our community faces regarding insurance coverage. They do truly want to benefit our nation's citizens and do what's best for our PKU patients. It was inspiring to potentially be a part of a change that we have yearned for for decades. Even though each meeting seemed short, I felt as though we broke some major barriers and achieved more in just a day and a half than we ever could with social media posts, protests, or petitions.

Although we made huge strides in a short amount of time, our work is far from over. After we receive a cost from the Congressional Budget Office, we need to continue pushing this bill, encourage our community to call their congressmen, and set up more face-to-face meeting with our representatives. The harder we work during this phase, the more likely we are to have this bill introduced to the caucus and voted on. We are open to more young advocates and hope all PKU college students and young adults will join us in our quest.

We are so motivated by our experience and are ready to take on this challenge to work our hearts out to get this bill passed for our fellow PKU families across the nation!



Jumping for Genes!

Our Jumping for Genes: Jump for PKU Fundraiser was the first fundraiser of our 2017 seasons. Jump!Zone was extremely generous to redirect all admission fees of families who mentioned PKU Illinois straight back to the organization. We had a fine turnout with 15 families coming to jump and play during the day. Jump!Zone also was kind enough to donate an extra \$250 on top of attendees fees, so we raised over \$400 for the day jumping and playing and having a great time! We'll have another event at Jump!Zone next year. Thanks for everyone who attended and to the folks at Jump!Zone for their generosity!!



Family Fund Day 2017

"At least it didn't snow!". Despite the rainy start to the day, the 2017 Family Fund Day was a success! May 20th, 82 individuals from all over the state of Illinois and some other adjacent states as well joined us for our annual Family Fund Day benefiting National PKU Alliance research fund. Together we raised approximately \$3,000 for research. Next year we will likely be switching Family Fund Day to early June in hopes of getting better weather!



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Sign up for your COMPLIMENTARY welcome box containing a variety of full size Mevalia products at <http://www.mevalia.com/us/resources/welcome-pack/register-now/>

PLEASE CONNECT WITH US at <https://www.facebook.com/MevaliaUS>

Products available through our online store <http://shop.mevalia.com/>

Lil's Dietary Shop and PKU Perspectives, so you can get DSCC coverage too!



PKU Parent Café Follow Up



This year's New Parent Café was filled with parents, PKU youngsters, and siblings of all ages. It was held at Grounds for Hope Café in Lisle, a warm and welcoming facility which had a large back room which was a perfect backdrop for the event. The room was filled with vendor tables, a scrumptious PKU-friendly breakfast spread complete with delicious low-protein waffle bar, and of course, coffee! There was room for the children to explore and tables arranged to facilitate lots of discussion among parents and other guests. The event had 41 attendees, including 15 families with PKUers ranging from 11 months to 23 years. A great turnout and an inspiring morning for all.

The families shared and compared experiences of life with PKU, focusing on topics ranging from PKU friendly restaurants for all ages, to the Medical Nutrition Equity Act. PKU adults as well as families with older children with PKU provided advice and encouragement to some of our newest PKU families. And, our newest PKU families, reminded those who have been around PKU for a long time how helpful it is to have a strong support organization like the PKU Organization of Illinois supporting everyone touched by PKU.



Margaret Hovland of Cambrooke Therapeutics captivates the audience while reading, *The Adventures of Ruby Pricklebottom*.

We are thankful to the vendors for their active support in providing for the PKU community. Nutricia Metabolics, BioMarin, Cambrooke Therapeutics, and VitaFlo all had tables at the event where they provided information and samples to families. We are also very thankful for Mevalia, who provided boxes full of low-protein pasta, pizza crust, bread, fruit bars, and other fun goodies to be distributed to guests. Each guest also was able to leave with a "goodie bag" and folder full of samples, recipes, information, and tools for everyday life with PKU thanks to these outstanding vendors and the PKU Organization of Illinois board members. We also extend our sincere gratitude to the metabolic teams at UIC and Luries for taking the time to attend and answer questions. We hope to see you all at next year's Parent Café!

BD's Mongolian Grill Fundraiser

This past June marked another successful fundraising event at BD's Mongolian BBQ in Naperville. We had 5 members of our PKU community join forces with the grill team, and try our hand with the large flat top grills and grilling swords. It is a lot tougher than it looks! We learned how to cook meat, veggies, and even crack an egg using their very unusual tools. We got the hang of it pretty quick and cooked all the meals for all the guests that came in to the restaurant that night. Mongolian BBQ donated \$3 for every person who mentioned that they were with the PKU organization of Illinois, and we also split the tip jar with the rest of the grillers at the end of the night as well. Not only did we raise funds for PKU research and our events, but we also raised awareness and educated A LOT of people that night. Many guests visited our tri-fold board and asked our guest grillers questions as we prepared their meals. Overall, it was a definite success and we cannot wait to see you there next year!





Recipes from the Board



Cheesy Hash Brown Casserole

Approximately 9 servings

Phe: 34mg phe per serving (1/9 pan)

Ingredients:

- ½ cup so delicious coconut creamer
- 2 Tbsp. Earth balance soy free buttery spread
- 2 T corn starch mixed with ¼ cup water
- 1 packet George Washington Golden Broth Mix
- 30g Follow Your Heart Cheddar Cheese
- 30g Chao Creamy original slice
- 200 g. Frozen Cubed Hash Brown
- 1 Cup cooked Cambrooke Rice

Cool low protein rice after cooking, according to package directions. Measure potatoes and set aside.

Heat Creamer and butter in pan until butter is melted

Heat and stir in G. Washington broth mix and then the cornstarch mix

Stirring constantly, until thickened slightly

Add in cheeses and mix well.

Add potatoes and low protein rice, mix well

Place in 9x9 casserole dish lightly sprayed with Pam

Bake 30 minutes

Mushroom Burger or “meatballs”

Yields 6 burgers or 24 “meatballs”

Phe: 54mg per burger patty (56 g each) or per 4 meatballs (14 g each)

Ingredients:

- ½ small onion cut into 4 pieces (130 g)
- 1 large clove garlic, roughly chopped
- 1 Tbsp. olive oil
- 285g fresh white or brown cremini mushrooms, quartered
- ½ cup low protein rice or cooked low protein spaghetti of choice (75g)
- 12 g fresh low protein bread crumbs
- 2 tsp. Worcestershire sauce
- ½ tsp. salt
- Pepper
- 1 Tbsp. low protein egg replacer powder
- Butter

Directions:

Combine the onion and garlic in food processor. Using the pulse button, process until the onion and garlic are evenly chopped into pieces that are about 1/8 inch in size

Heat oil in large skillet over medium heat. Add the onion and garlic and sauté for 7 minutes. Meanwhile, process the mushrooms in the food processor, using the pulse button until they are about 1/8 inch in size

Add the mushrooms to the onions and cook, stirring frequently, for 10-12 minutes or until the water in the mushrooms has evaporated. It is important that the mushrooms are cooked until they are dry, or the burgers will not hold together

While the mushrooms are cooking, put the cooked low pro rice or cooked spaghetti in the food processor. Again, use the pulse button and chop the rice or spaghetti into little pieces. Don't run the processor too long, or you'll just get a very sticky blob. When the mushrooms are cooked, add the chopped rice or spaghetti and stir, then add the bread crumbs, Worcestershire sauce, salt and pepper to taste. Mix well and adjust seasonings as needed.

Using a ¼ cup measuring cup, measure out six ¼ cup scoops of the mushroom mix and form burgers. Or, if desired, roll out 24 - 14 oz. balls to form “meatballs”

In a non-stick skillet, melt 1 tbsp. butter over medium high heat. When the foam subsides, add one or more burgers and fry for about 2-4 minutes per side, until golden brown. Fry the remaining burgers, adding butter to pan as needed. Freeze extra burgers individually wrapped in wax paper in a plastic freezer bag

BENEFIT TO RAISE FUNDS "FORE" PKU



TOP GOLF NAPERVILLE

SUNDAY
SEPTEMBER

17TH

3:30 - 6:30



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NAPERVILLE, IL
60563

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\$175/COUPLE
\$300/FOURSOME

INCLUDES FOOD AND GOLFING

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SATURDAY, OCTOBER 7, 2017
5:30 -9:00 IN THE EVENING

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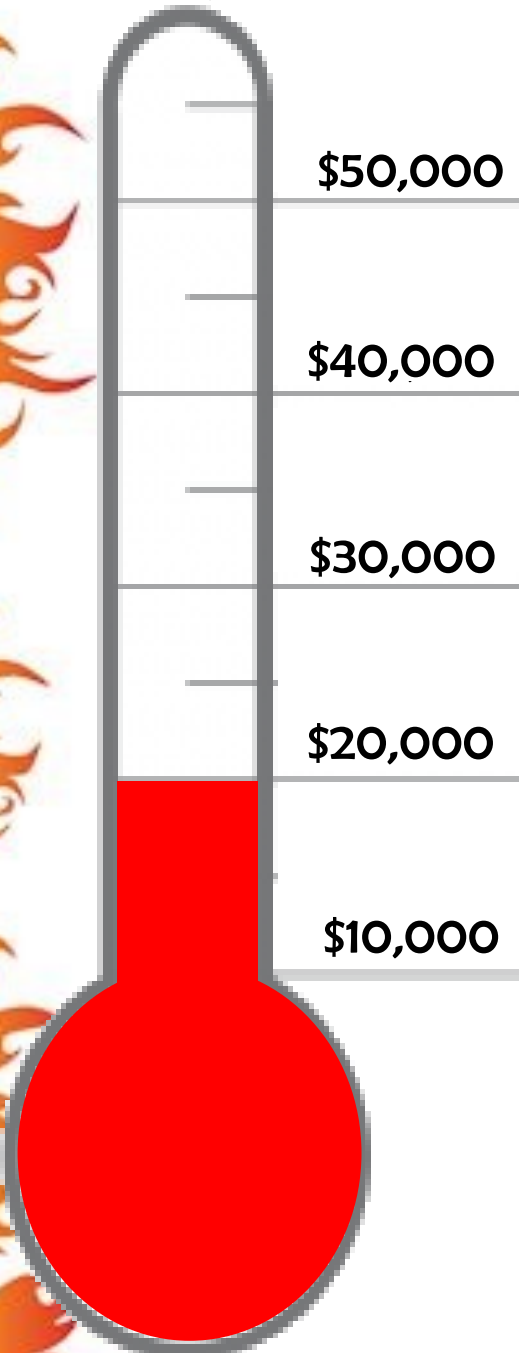
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How will it be spent?

\$2,000 CookforLove.org
\$3,000 How Much PHE
\$7,000 Clinics
\$8,000 Scholarships
\$10,000 NPKUA Research Fund
\$30,00 Operating Cost
(Operating cost includes the price of events)

Donation Levels

Hazel Vespa: \$100

Barbara Burton: \$250

Brenda Winiarski: \$500
(Cook for Love founder)

Virginia Schuett: \$1,000

Pearl S Buck: \$2,500
(Author of "the Child who never Grew")

Dr. Robert Guthrie: \$5,000

Dr. Asborn Folling: \$10,000
(Founder of PKU)

Send donations to:

PKU Organization of Illinois
P.O. Box 102
Palatine, Illinois 60078

TOP SECRET

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PKU Organization of IL presents
2017 Annual Meeting

Mission: POSSIBLE

Keynote: "Updates on PKU Gene Therapy"

Today Daelyn Richards will present her research which aims to address the current limitations of DNA based adeno-associated virus (AAV) gene therapy, as well as explore the new CRISPRcas9 technology to treat phenylketonuric mice.

What to Expect:

- 1) Keynote Speaker: Daelyn Richards "Updates on PKU Gene Therapy"
- 2) Cooking Demonstration: Chef Rachel Merz
- 3) Breakout Sessions
- 4) Raffle, Scholarship Winners, & Vendor Tables.
- 5) Children's Program for kids 6-12
- 6) Light breakfast and lunch will be served

Save the Date!

Saturday, November 4, 2017
9:00 – 4:00pm (8:15am Registration)

DoubleTree Suites by Hilton
Hotel & Conference Center
2111 Butterfield Rd
Downers Grove, IL 60515

CLASSIFIED

Timeline of Events

8:15

Registration
Visit Vendors
Light Breakfast

9:00

Program begins
Welcome &
Year in Review
Board Member Review

9:15

NPKUA Update

9:45

Keynote Speaker
Daelyn Richards

10:45

Vendor Break

11:00

Breakout Sessions

12:00

Lunch

1:00

Cooking Demo
Guest Chef:
Rachel Merz

2:00 Panel

3:00

Clinic Updates
Children's Program

3:30

Raffle,
Scholarship Winners,
Final notes for the
year

Register at:

PKUIL.org
Adults: \$35
Kids: \$25

Daelyn Richards received her Bachelor of Science in Molecular and Microbiology with Honors from Portland State University in 2014. She is currently a doctoral candidate at Oregon Health and Science University in the Department of Molecular and Medical Genetics. She is working in the area of gene therapy in the laboratory of Dr. Cary Harding. Dr. Harding's longstanding research focus is improving therapies for peoples with inborn errors of metabolism, including phenylketonuria (PKU), and is recognized for his efforts in translating these therapies into the clinic. Today Daelyn Richards will present her research which aims to address the current limitations of DNA based adeno-associated virus (AAV) gene therapy, as well as explore the new CRISPRcas9 technology to treat phenylketonuric mice.



Daelyn Richards

Rachel Merz, 27, diagnosed with non celiac gluten sensitivity four years ago, personal chef, main focus is on gluten free/sensitive recipes, serve safe common allergy food handling certified.

As a child, cooking a meal automatically meant family bonding time. This was the inspiration behind the decision to attend the Le Cordon Bleu school of culinary arts. Attending school nourished my culinary and knife wielding skills which allowed me to work for some lovely families along the north shore. I currently focus my time on my side business of dog walking and pet sitting and baking yummy gluten sensitive cookies, cakes, and dog treats! I chose to volunteer as the guest chef, because a very close family member has children with PKU. I'm fascinated and moved by the amount of time and effort she puts into the wonderful meals she prepares for her children.

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Dear Phebea:

Is My Formula Really Important?

Dear Phebea, I am 16 years old, and my parents and doctors have been telling me ever since I can remember how important it is for me to drink my formula. Most of the time, I listen to them and take everything I am supposed to, even though I think it's disgusting. About a month ago, though, I wanted to see what would happen if I stopped taking it, so I've been throwing it away. The funny thing is that I don't feel sick at all – in fact, nothing has changed. Is it really so important for me to drink my formula? What would happen if I stopped taking it for good?

Thanks,
Don't Tell My Mom

Dear Don't Tell My Mom: This is a very common question that many patients ask. One of the hardest parts about following the diet for PKU is that, very often, formula noncompliance does not produce any noticeable effects... at first. Most people usually do not feel physically sick or have a hard time going about their normal days. Your parents and doctors are right, though – drinking your formula is one of the most important things you must do in order to successfully manage your condition. Here's why:

1) **Drinking formula is a way to assure that you are getting enough protein.** Although following a low protein diet is incredibly important for management, it places you at increased risk for protein deficiency. Taking in too little protein can have serious consequences. These include poor concentration and lethargy, dry and flakey skin, and – the most serious of all – muscle breakdown. When you take in too little protein, your body breaks down your own muscle. Amino acids levels in the blood increase, including phenylalanine which is something you certainly do not want! Drinking your formula helps you to maintain lean body mass by supplying enough total protein to meet your needs.

2) **Your formula is your best source of vitamins and minerals.** Major food groups, including meat, dairy, beans/legumes, and many high protein grains are restricted on your diet. Think about your formula as a multivitamin. For example, it gives you the calcium that you can't get from a glass of milk, and the iron that you can't get from red meat. Vitamin and mineral deficiencies can place you at risk for health complications such as osteoporosis and iron deficiency anemia.

3) **Your formula helps to keep you full.** Without your formula, it's very likely that you will be hungrier as a result of taking in fewer calories and protein. And what do we all do when we're hungry? We eat more! An increase in your protein intake from food above what your doctor and dietitian have recommended for you will cause an increase in your phenylalanine levels. So, drinking your formula when you are hungry rather than reaching for a higher protein food will help to keep your levels under control.

I hope this is helpful. Don't forget that your dietitian stays up-to-date with available formulas on the market and can recommend new products that you might prefer in terms of taste and convenience!

Sincerely,
Phebea



PKU PATIENT REGISTRY

The National PKU Alliance (NPKUA) has created this registry as part of its mission to improve the lives of individuals with PKU and pursue a cure.

The PKU Patient Registry is a patient-driven, natural history study that consists of electronic surveys to collect information about the patient experience and disorder progression. Patients, or their caregivers or guardians, can enter information from anywhere in the world. The data is made anonymous and stored securely in an online portal called a registry. The NPKUA may share the data with individuals or institutions conducting research or clinical trials as approved by the study's governing board that includes scientists, doctors and patient advocates.

Join us to help accelerate research for PKU and find a cure! <http://pku.iamrare.org>

National PKU Alliance
NPKUA.org



Phone: 715-493-0074
Fax: 715-453-7670
Email: registry@npkua.org



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Updates from the Clinics

 Ann & Robert H. Lurie
Children's Hospital of Chicago®

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University of Illinois, Chicago

The University of Illinois Genetics and Metabolic clinic continues to have strong outreach program through the satellite clinics. In addition to our Chicago based clinic, we see patients in Rockford, Oak Lawn, Naperville, Springfield and Peoria. Our physicians include Dr. George Hoganson, Dr. Zohra Shad and Dr. Gifty Bhat. Our team of genetic counselors include Rich Dineen, Maria-Renee Plona, and Elizabeth Kaplan in Chicago, Jennifer Burton in Peoria and Gina Morley in Rockford. Our team of dietitians includes Krista Engen, Katherine Ingle, and Shannon O'Brien in Chicago and Diane Simon in Rockford. Our clinic coordinator is Olivia Villareal. This year we were excited to welcome Krista and Katherine as our newest members to the team. Please see their bios below.



Krista Engen, MS RD LDN

I have been a registered dietitian since 2011. Born and raised in the Chicago suburbs, I completed my undergraduate degree at the University of Illinois in Urbana Champaign. I moved to Oklahoma for two years to complete my master's degree in Nutritional Sciences and my dietetic internship at Oklahoma State University. Following my graduate work,

I moved back to the Chicago area where I began working in nutrition research in the Gastroenterology & Nutrition department at Rush University Medical Center. It was at Rush that I met my now-husband, who was assigned to give me a tour of the research lab on my first day of work! We got married July 2016 and enjoy living in Chicago. We love to go for walks along the lake and enjoy all of the wonderful things that Chicago has to

offer. I have always had a strong interest in pediatric nutrition, and was thrilled to join the metabolic genetics team at UIC in November 2016! I love working with children and their families, and I am enjoying learning something new each day.



Katherine Ingle, RD LDN

I grew up in Massachusetts and graduated from the University of Vermont in 2015. Shortly after graduation, I moved to Chicago to complete my Dietetic Internship at the Hines VA Hospital. As part of my internship, I completed a brief rotation in pediatrics

at Lurie Children's Hospital where I shadowed the metabolic team. After this experience, I had a strong interest in pursuing a career specializing in pediatric metabolic genetics. When a position became available at UIC, I knew it would be a perfect fit. When I am not on the clock, I enjoy traveling, exploring Chicago and trying new restaurants!

Lurie Children's

At Lurie Children's we have three new members of the PKU team:



L to R: Shanna Widera, Viera Shively, and Fayth Kalb.

Vera Shively, MS is an Education Project Coordinator in the Division of Genetics, Birth Defects and Metabolism at the Ann & Robert H. Lurie Children's Hospital of Chicago. She earned a Bachelor of Science in biology and a Master of Science in biology and chemistry education from Purdue University. Recently she completed a Master of Science in Health Communications from Northwestern University. For many years Vera worked as a Senior Research Associate in the Department of Surgery at Northwestern University. There she studied the molecular and cellular biology of vascular disease.

Vera began her work at Lurie Children's in November 2016. The Education Project Coordinator supports the physicians, dietitians, genetic counselors and nurses in several ways. Primarily, she works with clinicians to design educational materials for patients and their families. Projects take on a variety of forms including the creation of handouts, metabolic crisis protocols for emergency personnel and even educational games for patients to play during their clinic visit. In addition, she assists in the submission of manuscripts for publication in professional journals. Vera also provides continuing education for her colleagues in Genetics through regular lunchtime presentations. Recent topics have included CRISPR technology, gene therapy and anti-sense oligonucleotide therapy.

She enjoys being part of the Lurie Children's PKU Team, and is looking forward to PKU-Palooza, an event

for teens and their parents on July 13th. Vera Shively and her husband have 2 grown daughters and live in the Western suburbs.

Shanna Widera is a nurse practitioner in the Division of Genetics, Birth Defects and Metabolism at Ann & Robert H. Lurie Children's Hospital of Chicago since 2001. Shanna serves as a Sub Investigator for multiple Genetics studies, including PKU. She coordinates infusions of enzyme replacement therapy in the Ambulatory Infusion Center. She received her Bachelor of Science in Nursing from Saint Mary's College, Notre Dame, Indiana and Master of Science in Nursing from University of Wisconsin at Madison. She is certified by the Pediatric Nursing Certification Board. She is a member of International Society of Nurses in Genetics (ISONG) and National Association of Pediatrics Nurse Practitioners (NAPNAP). She will be increasing her involvement in the medical management of patients who are followed in the PKU clinic, and is looking forward to working with the Lurie's PKU team to provide them care and support.

Fayth Kalb is a genetic counselor who recently graduated from the University of South Carolina. Fayth has been with the PKU clinic for about 7 months now providing education, counseling, and care coordination. She has truly enjoyed getting to work with all of our wonderful PKU patients and families and is very happy to be a part of such a great team here at Lurie Children's!

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2018 PKU Press Renewal

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City: _____ State: _____ Zip code: _____

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