The National Organization for Rare Diseases (NORD), Inc® is a not-forporbit health agency dedicated to the identification, treatment, and cure of rare "orphan diseases" such as PKU through education, advocacy, research and patient services programs.

MOKD (National Organization for Rare Www.RAREDISEASES.ORG 1-800-999-6673

The Mational PKU Alliance works to improve the lives of individuals and families associated with PKU through research, support, education and advocacy while ultimately seeking a cure.

1-877-NPKUA-22 WWW.NPKUA-22

### National PKU Alliance

PKU.com provides comprehensive information about PKU. Log on today and join the discussion and to make new PKU friends. Join at PKU.com.

PKU.com WWW.PKU.COM

### **PRUBLES OURCES:**

#### Indication

KUVAN® (sapropterin dihydrochloride) Tablets is approved to reduce blood Phe levels in patients with hyperphenylalaninemia (HPA) due to tetrahydrobiopterin- (BH4-) responsive Phenylketonuria (PKU). KUVAN is to be used with a Phe-restricted diet.

### **Important Safety Information**

High blood Phe levels are toxic to the brain and can lead to lower intelligence and decrease in the ability to focus, remember and organize information. Any change you make to your diet may impact your blood Phe level. Follow your doctor's instructions carefully. Your doctor and dietitian will continue to monitor your diet and blood Phe levels throughout your treatment with KUVAN.

If you have a fever, or if you are sick, your Phe level may go up. Tell your doctor and dietitian as soon as possible so they can see if they have to adjust your treatment to help keep your blood Phe levels in the desired range.

KUVAN is a prescription medicine and should not be taken by people who are allergic to any of its ingredients. Tell your doctor if you have ever had liver or kidney problems, are nursing or pregnant or may become pregnant, have poor nutrition or are anorexic. Your doctor will decide if KUVAN is right for you. Tell your doctor about all the medicines you take.

The most common side effects reported when using KUVAN are headache, diarrhea, abdominal pain, upper respiratory tract infection (like a cold), throat pain, vomiting, and nausea.

To report SUSPECTED ADVERSE REACTIONS, contact BioMarin Pharmaceutical Inc. at 1-866-906-6100, or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Please read the attached Patient Information.



# YOU are Invited!



# Please join us for an exciting event designed to provide people with PKU and their families an opportunity to

- Discuss the importance of managing your
   PKU and the impact it has on your daily life
- Learn about KUVAN® (sapropterin dihydrochloride) Tablets and support services available to help you with your treatment
- Meet other people with PKU and their families
- Ask your PKU questions of local healthcare professionals and people just like YOU



### speakers

Mitzie Grant, PhD
Psychologist
Director, Pediatric
Drexel University College of Medicine
Philadelphia, PA

Nicole Payne, RD, LDN
Metabolic Dietitian
Division of Medical Genetics
Children's Hospital of Pittsburgh
Pittsburgh, PA

Kathleen Maguire Cornwall, NY

# **REGISTRATION**

There are no registration fees for this event.

### Register for this program

- WEB www.symbiotixonline.com/PKUTH
- **Phone** (800) 396.9577
- Email
   PKUTH@symbiotixonline.com



## event details

Sunday, April 18, 2010 Baltimore Marriott Waterfront

700 Aliceanna St Baltimore, MD 21202 (410) 385-3000

9:30 AM Registration
10:00 AM Town Hall Meeting
11:30 AM Lunch at the ESPN Zone
(Low phe provided)

Immediately following the Town Hall, tickets will be provided (limit 4 per family) for the ESPN Zone Game Room