## **Prescribing Diets to Treat Rare Diseases**

August 05, 2009 1:30 AM Arthur Nead anead@tulane.edu

Eating right is essential for healthy living, but for some people, a proper diet is literally a matter of life or death. Metabolic dietitian Amy Cunningham serves patients in Louisiana who have inherited metabolic diseases that require highly specialized and restricted diets.

"Our patients come to us mostly through newborn screening," says Cunningham, who is on staff in the <u>Hayward Genetics Center</u> at the Tulane University School of Medicine. Hospitals take a blood sample from all newborns. Louisiana currently screens for about 30 different diseases.

## Tulane metabolic dietitian Amy Cunningham talks about her lifesaving work to help patients with metabolic diseases in this video with photography and production by Paula Burch-Celentano.

"If the state newborn screening lab gets a sample that raises a red flag, then they send that to us. We do a more targeted confirmatory laboratory analysis, and that tells us if a child has a specific disease or not. If a child is diagnosed with a metabolic disease, then care is started immediately," she adds.

The diseases that are treated by the Hayward Genetics Center clinical team are inherited and cannot be cured. The only recourse is to manage them with special diets and medications. And these diseases are very rare. The Hayward team treats approximately 200 patients from throughout Louisiana and the Gulf Coast.

"Most of these kids have an enzyme that doesn't work," explains Cunningham.

For children with PKU, for example, there is a particular enzyme that breaks down an amino acid in the body. Without it, the amino acid builds up and becomes toxic in the brain, resulting in mental retardation without appropriate treatment from birth. Nearly all natural protein must be eliminated from their diet. A metabolic dietitian like Cunningham makes sure these children receive specially formulated foods to provide them with the correct diet throughout their entire lives to remain healthy.

Cunningham is the only full-time metabolic dietitian in Louisiana, and she is one of only approximately 250 metabolic dietitians in the entire United States. She helped found a support organization for these professionals ? Genetic Metabolic Dietitians International ? and she will serve as president in 2010â?"11.