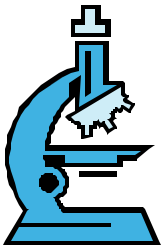

# Discovering PKU

Long ago, before you were born, doctors and scientists did not know about Phenylketonuria (PKU). PKU was not discovered until 1934, by a doctor from Norway named Dr. Fölling. Dr. Fölling knew two children from the same family that had very similar problems. Dr. Fölling had met several other children with the same problems as these two children. He knew that all of these children had the same thing. However, he did not know what it was.

Every day Dr. Fölling worked in has lab trying to find out what made these children similar. He ran hundreds of tests using test tubes and his special lab equipment. Many times he thought he had discovered something, but he really had not. Fortunately, Dr. Fölling never gave up. He kept trying. Test after test after test, until finally he discovered what those children had in common. He called it Phenylketonuria, or PKU for short.

After his extraordinary discovery many other doctors and scientists began to learn more about PKU. These doctors and scientists learned that PKU is genetic. Genetic means that certain families are more likely to have children with PKU. They also learned that people with PKU cannot use phenylalanine (phe). They knew that the high blood phe levels caused the problems.

These bright young doctors and scientists thought that maybe less phe from foods would lower blood phe levels. In 1953, Dr. Bickel fed a low phe diet to a little girl with PKU. He noticed many wonderful changes in the girl when she drank her low phe formula and ate only low phe foods. Dr. Bickel knew she was healthy because her blood phe levels were low. This was an extremely exciting discovery. Everyone thought all children with PKU should follow a low phe meal plan. The only problem was that it was not clear who had PKU and who did not. That is when Dr. Guthrie became involved.

In 1962, Dr. Guthrie found an easy test for checking blood phe levels. This test is done on newly born babies. It helps the doctors know who has PKU and who does not. If testing was not done, no one would know they had PKU until too late. It is

important to begin the low phe meal plan soon after birth. Dr. Guthrie's test is still used today. Some of you may even do Guthrie tests at home.

At first, no one knew how much formula or how much phe from food was right for children with PKU. Many doctors and nutritionists worked together to find out what was best. They tried different amounts of phe from food and different amounts of formula. At first, not everything worked just right. At one point, they allowed some children to eat high protein foods. They quickly decided this was not a good idea. They found out how important the special meal plan is for children with PKU.

These doctors and nutritionists were trying to find the right combination of formula and food. This combination would help children with PKU keep their blood Phe levels low. Then children with PKU would grow and play just like children should. After lots of hard work, the perfect combination of formula and food was found. Most important was to drink the formula. They also decided that a variety of low phe foods was important too.

It took a long time to learn so much about PKU. You now know more about PKU than Dr. Fölling did You also know more than Dr. Bickel did about how to keep your blood phe levels low. Now, you also know that Dr. Guthrie's test is what helped you begin your low phe meal plan soon after birth. And most of all, you understand that low blood phe levels are best!

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