20531 SW Prindle Road Tualatin, OR 97062

April 6, 2013

To Whom It May Concern:

My son, Chad, age 42, was diagnosed at age one year with Argininosuccinic Aciduria (ASA), a very rare metabolic disease. We were fortunate enough to live in the Los Angeles area and were referred to the UCLA Medical Center, where a genetic specialist was able to pinpoint Chad's very serious condition. We were told at the time that he was the first case west of the Mississippi River to be diagnosed with this disorder. After one year of serious illness and many referrals to specialists and clinics, this was a breakthrough and a blessing to us, where Chad was finally in the hands of a physician and medical staff who were able to help us with medication and diet to keep him alive and able to progress, although he was seriously behind developmentally.

Fast forward five years, when we relocated to the Portland area and were referred to the OHSU Metabolic Clinic at Children's Development and Rehabilitation Center. At that time, there was one metabolic physician at the Clinic, but we were accepted and were assisted with all of Chad's medical needs. In the ensuing years, the Metabolic Clinic has increased to four physicians, as more children with metabolic disorders have been diagnosed, and treated there. Chad has had many occasions of metabolic crises due to his disease, which have necessitated hospitalization, always beginning at the emergency room at OHSU. On most of those occasions, Chad's metabolic physician has met us there and has filled in the ER doctors on Chad's very rare and serious condition, and what his needs would be as a patient. In all of those cases, the emergency room doctors were educated by the metabolic physician, and clearly would have had no idea how to treat Chad, as they had no knowledge of his rare disorder.

I honestly don't know what we would have done without the doctors and staff at the Metabolic Clinic to get us through our many difficult challenges over the years. I don't know of any other medical facility in the Portland area that specializes in rare metabolic diseases, and it has been our good fortune to have relocated here and receive such wonderful help from the OHSU Metabolic team for the past 35 years.

Sincerely,

Betty A. Bode

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