



Dear Senator Monnes Anderson and members of the Senate Committee on Health Care,

We are writing to express our support of Oregon SB 215 which will set up a data base called ORDER (Orders for Rare Disease Emergency Response).

When health care personnel are unfamiliar with a rare or chronic conditions, delays and mistakes in treatment can occur. Since there are over 7,000 rare conditions, even the most gifted of health care providers will not be familiar with each and every rare or chronic condition.

Many patients with rare or chronic conditions require specialized care which is different from the “standard procedures” of many Emergency EMS, ED and Urgent Care facilities. In emergency and/or surgical situations health care providers will be able to look up the ORDERS of those patients who may need specialized care and read the instructions of the patient’s long term care provider. Providing immediate access to specific instructions will reduce complications and save lives.

We believe SB 215 would be of benefit to our community and urge you to support the bill.

### **SIGNED BY THE FOLLOWING ORGANIZATIONS**

National Organization for Rare Disorders NORD  
Adrenal Insufficiency United  
(Representing over 60+ conditions which can cause adrenal insufficiency)  
Craniopharyngioma Group (Brain Tumors)  
Danny’s Dose (Hemophilia and bleeding disorders)  
MAGIC Foundation (Representing over 17 rare disorders)  
MLD Foundation (Metachromatic Leukodystrophy)  
National Adrenal Diseases Foundation NADF (Addison’s Disease)  
National Foundation for Ectodermal Dysplasias nfed  
National Leiomyosarcoma Foundation  
Mollaret’s Meningitis Association  
Timothy Syndrome Alliance