



European  
Reference  
Network

MetabERN

European Reference Network  
for Hereditary Metabolic Disorders

## Webinar

# “Emergency Protocols for FAOD and GSD”

**23 June 2020**

**16:00-17:30h CEST**

*How can you prevent emergencies at home? How can you contact the hospital directly?* Metabolic emergency situations should be prevented as much as possible. The CONNECT MetabERN project has been granted in an eHealth call ([2018-EU-IA-0173](#)). Metabolic specialists have collaborated in an activity regarding “emergency protocols” to automatically generate emergency letters for patients with fatty acid oxidation disorders (FAOD) and glycogen storage diseases (GSD).

### Target Audience:

Parents, carers and patients with FAOD and GSD.

### The Aims of the Webinar are:

1. to inform about the project
2. to demonstrate how your emergency letter could be made
3. to address questions

### Registration:

Zoom Webinar ID: 861 6088 3921

### Remarks afterwards:

[info@stofwisselingsziekten.nl](mailto:info@stofwisselingsziekten.nl)

### Panel Members:

Bas te Boekhorst, Enrique L. Contreras Pulido, Hanka Dekker, Terry Derks, Sarah Grünert, Diego Martinelli, Maurizio Scarpa, Maren Thiel

### Program:

16:00-16:15 Introduction by Maurizio Scarpa and Terry Derks  
16:15-16:30 Explanation how to use the emergency letter in practice by Enrique L. Contreras  
16:30-16:45 Live demonstration by Bas te Boekhorst  
16:45-17:30 Questions & Answers by Panel Members