**Syllabus**A 5-Week Self-Paced Course  
  
Course Title: **CHARGE Syndrome: Information for Caregivers**Day(s) and time of classes – Online/Self-Paced

**Instructor:** Perkins eLearning

**COURSE DESCRIPTION:**

This online workshop has been developed to provide basic information for people who are providing direct care for children/adolescents/adults with CHARGE Syndrome or for parents who are just beginning to learn about CHARGE Syndrome. The workshop will focus on the following four areas: physical consideration, communication considerations, behavioral considerations and developmental considerations.

**COMPLETION REQUIREMENTS:**

Perkins eLearning Self-Paced workshops include assignments, readings, quizzes, and a final assessment. Students are expected to be familiar with all material presented in the workshop, and to submit all assignments where indicated. There are 5 modules in the workshop, each with a variety of activities to assist the participant in learning about the four areas.

This learning format includes on-screen checkboxes to help you track your work.

**EVALUATION OR GRADING POLICY:**

All submitted material is reviewed by Perkins eLearning and is evaluated as having met the assignment requirements. Assignments are not individually evaluated or graded. Submitted assignments are not returned.

Assignments and assessments are evaluated on a Pass/Fail scale, and all requirements must be met to receive credits. There is no time limit to completing a Perkins Self-Paced Workshop. The lesson plan structure is suggested as the best approach to the material.

**TEXTS:**

Required readings are indicated in the lesson plans. Additional suggested reading is optional. There is no textbook or other material required for purchase for this workshop.

**LECTURES:**

Lectures are presented in the form of recorded presentations. Participants will watch the sections of the lectures indicated by the syllabus.

**QUIZ**

Each session of the workshop opens and closes with a quiz. Quizzes are not individually scored, but are required for completion of the course. Correct answered will be presented on the screen after a quiz is completed.

**LEARNING OUTCOMES / OBJECTIVES:**

Upon completion of the workshop, participants will be able to:

* Identify the major symptoms of and variations in presentation of CHARGE syndrome
* Describe several ways that CHARGE Syndrome may impact development, communication, and learning
* Identify several possible causes of unusual behaviors in individuals with CHARGE
* Describe a variety of teaching strategies/intervention approaches that may assist the care provider in communicating with and teaching individuals with CHARGE syndrome
* Discuss ways having a child with CHARGE impacts families.

**INSTRUCTIONAL STRATEGIES:** [Place an X for each strategy you use while teaching this course.]

\_X\_\_ Lecture (recorded) \_\_\_ Data Collection and Analysis

\_\_\_ Discussion/Questioning \_\_\_ Pre-Practicum

\_\_\_ Laboratory \_\_\_ Role Playing/Simulation

\_\_\_ Problem Finding/Solving \_X\_\_ Independent Learning

\_\_\_ Interviewing \_\_\_ Field Trips

\_X\_\_ Viewing or Listening

\_\_\_ Reflective Responses

**COURSE REQUIREMENTS**

The required assignments for this course are listed below. Please see the individual session description for more detail about each assignment. The learning platform also provides checkboxes that can help you monitor your completion.

**COURSE CONTENT / TOPICAL OUTLINE:**

Session One: **Introduction to CHARGE Syndrome**

**Session Goals:**

Upon completion of this session the participant will be able to:

* Identify the major symptoms of and variations in presentation of CHARGE syndrome
* Name the four major diagnostic criteria for CHARGE syndrome
* Explain the basic genetic cause for CHARGE syndrome

*Readings:*

1. About CHARGE

2. CHARGE Brochure

*PowerPoint:*

CHARGE Syndrome: An Introduction

*Webcast:*

Overview of CHARGE Syndrome: Pam Ryan, Perkins School for the Blind: (all six

chapters).

*Webquest:*

Explore the CHARGE Syndrome Foundation Website.

Session Two: **Physical Considerations**

**Session Goals:**

Upon completion of this session the participant will be able to:

* Identify the initial physical problems in CHARGE syndrome that pose a threat to survival
* Explain other physical and medical problems, including their management
* Describe sensory issues in individuals with CHARGE syndrome, and detail variations in how they may affect individuals
* Identify the initial effects on a family of having a child with CHARGE syndrome

*Readings:*

1. One Family’s Story, by Michelle Westmaas

2. The 1st 8 Family Stories from the *CHARGE Syndrome Management Manual*

*PowerPoint:*

Physical Considerations in CHARGE Syndrome

*Webcasts:*

1. Vision Issues for people with CHARGE syndrome: David Brown, California Deaf-Blind Services
2. Sensory Processing: David Brown, California Deaf-Blind Services

Session Three: **Communication**

**Session Goals:**

Upon completion of this session the participant will be able to:

* Describe several phenomena that get in the way of a child with CHARGE syndrome’s availability to learn and communicate.
* Define and utilize the Communication Bubble
* List and explain the types of communication modes typically used by individuals with CHARGE syndrome
* Define Total Communication and explain its importance
* Practice use of the Guidelines for Effective Communication
* Locate family support groups available to families with an individual with CHARGE syndrome

*PowerPoint:*

Communication

*Webcasts:*

1. Reflections on Deafblindness with Barbara Miles.
2. More reflections with Barbara Miles

*Webquests:*

1. American Speech and Hearing Association website
2. Explore a family support website linked to the CHARGE Syndrome Foundation’s website.

Session Four: **Behavior**

**Session Goals:**

Upon completion of this session the participant will be able to:

* Identify three possible causes of unusual behaviors in individuals with CHARGE syndrome.
* Describe several behavioral/personality commonalities that seem to have emerged in individuals with CHARGE syndrome
* Define the Behavior Threshold and explain some of the things that push an individual toward it.
* List common sources of pain in individuals with CHARGE syndrome, and explain why it is so important to pay attention to pain.
* Describe two ways that behavior that may look strange is actually helpful or may be a compensation strategy.
* List and use a variety of teaching strategies/intervention approaches to understanding or helping an individual with CHARGE syndrome who is experiencing pain or who is displaying unusual behavior.

*PowerPoint:*

Behavior in CHARGE Syndrome

*Webcasts:*

1. Behavior in CHARGE Syndrome: Tim Hartshorne, Central Michigan University
2. CHARGE Syndrome: The Impact on Communication and Learning: Martha Majors, Perkins School for the Blind. Watch all chapters!

*Webquest/Reading:*

Read an issue of CHARGE Accounts.

Session Five: **Development**

**Session Goals:**

Upon completion of this session the participant will be able to:

* Describe the differences between motor milestones (gross and fine) of typical children and of children with CHARGE syndrome
* Explain the relationship between “age at walking” and cognitive development
* Identify potential reasons why individuals with CHARGE may have difficulty with toileting and sleep.
* Describe the issues surrounding puberty (delay, osteoporosis).
* Explain some reasons why attachment might be difficult for a child with CHARGE syndrome.
* List and use strategies to assist individuals with CHARGE syndrome with social/emotional skill development.

**Week Five**

*PowerPoint:*

Developmental Considerations

*Webcast:*

Development: Teaching Strategies for Children: Sharon Stelzer, Perkins School for the

Blind: Watch all chapters.

Watch the German CHARGE Syndrome Group’s Adolescent and Adult Video

*Additional Video:*

“Delayed Gross Motor Development in CHARGE,” Nancy Hartshorne

*Reading:*

Stories #9-15 of the Family Stories from Manual