

Karen Windy, Editor
Fall/Winter, 2015

[The Rocha Family: CHARGE Syndrome Experience](#)

[By Johana Rocha, mother of Johan and Oscar, translated by Yolanda Lopez](#)



At the beginning of August we were fortunate to have the opportunity to experience our first CHARGE Syndrome International Conference and it was a magnificent experience full of lots of learning, but above all, full of lots of emotions. It is very difficult to describe what you really feel being there!

The conference was in Schaumburg, IL so we decided not to stay at the hotel and drive back and forth daily. It was tiresome, but very well worth it.

When we were walking towards the registration table I felt a huge knot in my throat, full of emotions thinking I was at last going to meet people just like us that went through and are experiencing the same things we are. I felt like crying and had a thousand memories going through my head.

The first day, even though we were very shy at the beginning, a few hours after being there, some of the other families approached us and expressed interest in meeting us.

It was heartwarming and comforting knowing that others were interested in knowing about us, and of course, we wanted to know about them.

The following days were phenomenal. There were so many classes to attend that I would've really liked to have more time to go to each one of

them. All were interesting subjects that related to all of the experiences and needs of our family. Unfortunately, we were unable to participate in all the ones we wanted to because most of them were scheduled at the same time, so we had to choose wisely. The good thing is that we learned so much out of the ones we did attend. At times it felt as a reminder of what we already know and as a reaffirmation that what we were doing was the right thing to do.

While we were in the classes our children were in camp. It was worrisome having to separate ourselves from our children, but I felt at ease knowing that they were in hands of professionals. Sometimes we worry about things that have not happened yet, and that is what does not allow us to enjoy ourselves. But my children were happy to be in camp. They had many fun activities every day!



I could spend hours explaining how fantastic this experience was, but I would never finish. The only thing there is for me to say is that if you have a child with CHARGE syndrome and you are yet to participate in one of the conferences, please do not hesitate to do so. Being there is worth every sacrifice! We are excited to go to the next one which will be in Orlando Florida in 2017.

Lastly, let me tell you that my most heartwarming experience being there was to realize how blessed we are to be parents of my Charger's. Not one person knows how to take care and help our children more than ourselves. That it is also so important to be ready or to seek information to help them even more! Also, knowing deep down inside that there will always be someone who will understand how difficult it is to bring up a child with multiple disabilities. Everything in this life has a reason to be, we are stronger than we think we are! We should never take at heart the diagnosis or prognostic a doctor gives us because sometimes it can create limits to our children abilities, so we should always know that the sky is the limit!!



OHOA Modules Starting Again February 2016!

Be sure to register by JANUARY 10, 2016!

WHAT IS A DEAF-BLIND INTERVENER?

Interveners...provide access to information and communication. They facilitate the development of social and emotional well-being for children who are deaf-blind. In educational environments, intervener services are provided by an individual, typically a Para educator, who has received specialized training in deaf-blindness and the process of intervention. An intervener provides consistent one-to-one support to a student who is deaf-blind (age 3—21) throughout the instructional day. (taken from INTERVENER SERVICES AND INTERVENERS IN EDUCATIONAL SETTINGS definition found on the National Center on Deaf-Blindness website at <https://nationaldb.org/>)

WHY IS LEARNING ABOUT DEAF-BLINDNESS AND INTERVENERS

IMPORTANT?

The Cogswell Macy Act was introduced in congress September 17, 2015. This act would make deaf-blind intervention a related service option for students with deaf-blindness in the US.

CAN FREE ONLINE TRAINING BE GOOD?

The Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules were created by a diverse group of experts in the field of deaf-blindness including state and national deaf-blind project staff, parents of children who are deaf-blind, higher education faculty, teachers, educational interpreters, and interveners. Each module includes a variety of accessible videos, photographs, slide presentations, and learning activities. ***As with any educational resource, the modules themselves do not constitute a formal training program, nor does completion of the modules independently and in isolation from a training program result in one becoming an intervener.

Project Reach: Illinois Deaf-Blind Services is offering the modules for professional development hours for licensed Illinois Teachers. The modules have been aligned with the new ISBE professional development requirements.

WHAT HAVE PEOPLE TAKING THE MODULE SAID?

"I liked learning about my particular student. I thought that was a useful activity".

"I loved the videos that showed parents/teachers talking and providing examples. The resources will be helpful with my students- deaf-blind or not".

"Enjoyed being able to work from home and at my own pace".

"Terrific support from the OHOA host".

"Loved the activities!"

"Explaining, what it means to be deaf-blind really gave me an understanding of my daughter. It gave me a better understanding of the disability".

WHEN DO THE MODULES START?

The Illinois cohorts will begin February 1, 2016 and end May 31, 2016.

While you may work on the days and times of your own choice, it is strongly recommended that you complete some work each week, and that you complete one module each month in order to complete all four modules within four months. Each module includes slides shows and videos to view, readings, assignments (some physical activities and most written) and other requirements to complete in order to receive 6-11 hours of credit per module. Once all four modules are completed, you will receive a certificate of completion/ISBE evidence of completion for all four modules.

Registration runs November 15, 2015 – January 10, 2016. Join now!

QUESTIONS? Contact:

Project Reach: Illinois Deaf-Blind Services

818 DuPage Blvd.

Glen Ellyn, IL 60137

Website: philiprockcenter.org

Email: mclyne@philiprockcenter.org

630-790-2484 voice 630-790-4893 fax

If you would like to take the Illinois Modules, please complete this application and return

it to Project Reach either by email, fax or mail listed on previous page.

SIGN ME UP FOR THE ILLINOIS 2016 MODULES!

NAME: _____

EMAIL _____

CITY _____

_____ Modules 1—4 _____ Modules 5—8 (must have completed 1-4 in a previous cohort)

I AM MAINLY INTERESTED AS A

_____ PARENT OF A CHILD WITH DEAF- BLINDNESS

_____ PARAPROFESSIONAL

_____ LICENSED TEACHER

_____ RELATED SERVICE PROVIDER/THERAPIST

_____ ADMINISTRATOR

_____ JUST CURIOUS

I agree to participate in these modules with other individuals from Illinois, including parents, paraprofessionals, teacher's therapists, administrators, and others. I

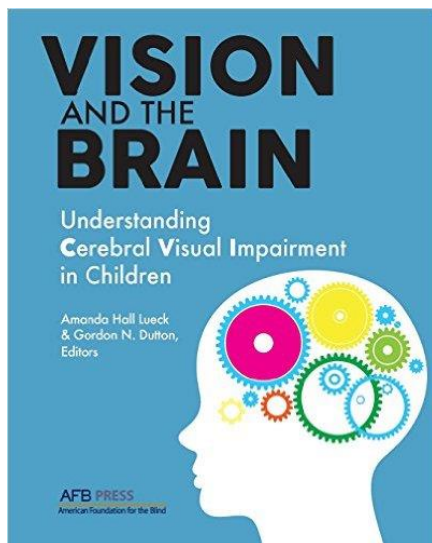
acknowledge that in order to receive a certificate of completion for each module as it is completed, a Project Reach staff will support me and confirm my progress in the modules.

_____ initials, please



New in the Library

***Vision and the Brain: Understanding Cerebral Visual Impairment in Children*, Amanda Hall Lueck and Gordon N. Dutton, Editors. New York: AFB Press, 2015**



In her review of Vision and the Brain published in the May-June Journal of Visual Impairment and Blindness, Elizabeth Dennison says that “This book was written in a way that teachers, therapists, and university instructors can understand, and I found the book to be straightforward in its presentation of information. I believe that the book will be very useful to direct service providers of children with CVI” (p. 242). While the book IS long (720 pages), it is full of useful

charts, and divided into logical sections. It is available for loan for one month at a time. Contact Peggy Pausche at ppauche@philiprockcenter.org to make a reservation.

Deaf-Blind 101 Do-It-Yourself Simulation Kit

This kit includes visual simulation goggles, the “Sensory Perspectives” 2-disk interactive DVD set, foam ear plugs, and suggested activities to do while using the materials. It is available for loan for one month at a time. Contact Peggy Pausche at ppauche@philiprockcenter.org to make a reservation.

SAVE THE DATES

IAER Pre-conference

“Cerebral Visual Impairment: Another Way of Seeing”, Amanda Hall Lueck, Ph.D.

February 17, 2016 9:00 am to 4:00 pm

Hyatt Regency Schaumburg Chicago

1800 East Golf Rd Schaumburg, Illinois

<http://il.aerbvi.org/>

2016 IAER Vision Conference

February 18-19, 2016

Hyatt Regency Schaumburg Chicago

1800 East Golf Rd Schaumburg, Illinois

Includes sessions by Project Reach staff

Carla Beck: All Children Can Read! A Tour of the Literacy Website from the National Center on Deaf-Blindness

Michelle Clyne: Deaf-Blind Difference: Taking What You Know Further for Your Students With Deaf-Blindness

<http://il.aerbvi.org/conference.htm>

American Foundation for the Blind Leadership Conference

March 3-5, 2016

Crystal Gateway Marriott, Arlington, VA

Cerebral/Cortical Visual Impairment: A National Conversation

Presenters: Chris Clark-Bischke, Ph.D., Director, Multi-University Consortium, University of Utah; Michelle Clyne, M.S.Ed., TVI, Deaf-Blind Specialist, EI, Coordinator, Project Reach: Illinois Deaf-Blind Services, Philip J. Rock Center and School; Mindy Ely, EL VISTA Project, Coordinator, Illinois State University; Christine Roman-Lantzy, Ph.D., Director, Pediatric VIEW Program, Western Pennsylvania Hospital, Pittsburgh; > Amanda Hall Lueck, Ph.D., Professor Emerita, San Francisco State University; Dr. Lotfi Merabet, OD, Ph.D., MPH, Director, The Laboratory for Visual Neuroplasticity, Massachusetts Eye and Ear Infirmary and Associate Professor of Ophthalmology, Harvard Medical School; and Mary Morse, Ph.D., TVI, Private Practice

<http://www.afb.org/info/about-us/events-and-awards/american-foundation-for-the-blind-leadership-conference-2016-2017/123>

Please return the following information to: Philip J. Rock Center and School

- Please make no changes to my address and keep me on your mailing list
- Please take my name off the mailing list.
- Please make the following changes on my mailing address label.
- Please add my name to the newsletter mailing list.
- Please mail me a large print edition of the newsletter.
- Please mail me a Braille edition of the newsletter.
- Please send me the newsletter in electronic format (email address required) _____

Name: _____

Parent/Job Title/Organization: _____

Address: _____

Telephone: _____

Email Address: _____

Comments:

***Philip J. Rock Center and School
818 DuPage Blvd.
Glen Ellyn, IL 60137***

**PRC is operated by
the Illinois State
Board of Education**

