



11th International CHARGE Syndrome Conference
Scottsdale, Arizona 2013

11th International CHARGE Syndrome Conference Saturday, July 27, 2013 Program Handouts



Category: Education

Saturday
Breakout Session #5:21: 10:45-11:45
Palomino 1 & 2

**Intervener Services for Children Who
are Deafblind: What's Happening**

Linda Alsop
Director Deafblind Programs
SKI-HI Institute/CPD
Utah State University

Presenter Information:

Linda Alsop is the Director of Deafblind Programs at the SKI-HI Institute at Utah State University in Logan, Utah and has extensive experience working directly with children with sensory loss and their families. She has been a classroom teacher of students with multiple disabilities, as well as a teacher of students with hearing impairments. She has been involved with Early Intervention Part C Programs and educational Part B Programs, and has coordinated statewide intervener services to children who are deafblind. She has developed numerous service programs, curriculum, and training materials that are being used by families, professionals, and paraprofessionals throughout the United States. She acts as a national consultant in deafblindness and is actively involved in national efforts related to intervener practices in the United States. She developed and implemented the first online training program in the country that trains interveners to work with individuals who are deafblind, and she established a National Intervener Credential through the National Resource Center for Paraprofessionals. She works closely with parents of children who are deafblind throughout the country, providing training, support, and resources related to educational laws and the rights of their children to have access to a Free and Appropriate Public Education.

Presenter Abstract:

Exciting News! The National Resource Center for Paraeducators is now offering a National Intervener Credential for paraeducators who have training in deafblindness and who demonstrate the competencies needed to work effectively one-to-one as interveners with children and youth who are deafblind. In this presentation, this new Intervener Credential will be described, along with the process of obtaining the credential based on the successful completion of a university intervener training program, a supervised practica, and a competency-based portfolio. The role of interveners with children and youth who are deafblind will be explained, and the university intervener training programs that are available online will be described. Also, information will be presented on how parents can advocate for intervener services for their children who are deafblind through the IEP process. Finally, national efforts to establish this practice as a credible service delivery option for children and youth who are deafblind will be discussed, along with how the existence of the Intervener Credential through NRCP supports these national efforts.

A Family's Guide to Intervenors booklet available at:

<http://intervener.org/wp-content/uploads/2012/06/A-Familys-Guide-to-Intervenors.pdf>

3rd Professional Day & 11th International CHARGE Syndrome Conference
Fairmont Scottsdale Princess Hotel, Scottsdale, AZ July 25-28, 2013

National Credentialing for Interveners Through the National Resource Center for Paraprofessionals

The requirements for obtaining the National Intervener Credential include:

- A minimum of **10 hours of credited coursework** from an Institution of Higher Education (includes a 2-credit hour practicum experience)
- A **practicum experience** (minimum of 2 credit hours) under the supervision of the course instructor and the guidance of a trained Intervener Coach
- A completed **Intervener Portfolio** based on the National Intervener Competencies which provides documentation that the intervener has acquired the knowledge and skills needed to be an effective intervener

Once the intervener has met all the requirements for credentialing, the Portfolio and other documentation is submitted to the National Resource Center for Paraprofessionals, along with a \$100 processing fee. If all requirements are met, the credential is awarded to the intervener.

Intervener Training

The Intervener training program is currently offered through Utah State University, Department of Communicative Disorders and Deaf Education.

The coursework is designed to be taken consecutively beginning with Introduction to Deafblindness.

- COMD 4660 Introduction to Deafblindness (4 credits)
- COMD 4840 Vision and Hearing Loss (4 credits)
- COMD 4250 Practicum Work Study

On-line Training Program in Deafblindness



A preservice online training program in deafblindness is available through Utah State University. Based on the National Intervener Competencies, the courses are designed to prepare paraprofessionals to work as interveners with children and youth who are deafblind. It can also be useful to teachers, parents, administrators, and adult service providers. This coursework won the 2007 Blackboard Greenhouse Exemplary Course Award, which recognizes it as one of the top ten online courses in the country.

The deafblind coursework is designed to be taken consecutively beginning with Introduction to Deafblindness.

Courses in Deafblindness

COMD 4660/COMD 6660	Introduction to Deafblindness (4 credits)
COMD 4840/COMD 6840	Vision and Hearing Loss (4 credits)
COMD 4890/COMD 6890	Additional Issues in Deafblindness (4 credits)
COMD 4250	Practicum Work Study (2 credits)

National Intervener Credential

For those wishing to obtain the National Intervener Credential, the following coursework is required at this time.

COMD 4660/COMD 6660	Introduction to Deafblindness (4 credits)
COMD 4840/COMD 6840	Vision and Hearing Loss (4 credits)
COMD 4250	Practicum Work Study (2 credits)

The following options are available to interested students:

Option 1: Students can take the training program in deafblindness that consists of three 4-semester credit hour classes to be offered in the Fall and the Spring. Undergraduate tuition is currently \$275/credit hour with no out-of-state fees (\$1,100/course). Upon successful completion of the coursework, students will be awarded a certificate of completion from USU. These courses can also be taken for graduate credit. Tuition rates for graduate credit is currently \$350/credit hour (\$1,400/course). **(Note: Tuition rates are subject to change.)**

Option 2: Students can take the coursework as part of an Associate's Degree program in General Studies with a Focus in Deafblindness. This online program includes 30 semester hours of general education classes and 30 hours of coursework that includes the deafblind classes and other related topics. If interested in participating in this training, please contact: Linda Alsop, SKI-HI Institute, (435) 797-5598, linda.alsop@usu.edu.

Option 3: Students can take the three-course training program on a **non-credit basis**. The cost for non-credit tuition is \$110/credit hour (\$440/course). Upon successful completion of the coursework, students will receive a certificate of completion from USU. **If you choose to take the course for non-credit, contact Fran Payne (435) 797-5591 or fran.payne@usu.edu for a non-credit registration form.*



Category: Medical/Genetics

Saturday
Breakout Session #5:22: 10:45-11:45
Palomino 3

Everything you want to know
about CHARGE and genetics

Nicole Corsten-Janssen, MD
Prof. Conny van Ravenswaaij, MD, PhD
Dept. of Genetics, University Medical
Center Groningen, Groningen,
The Netherlands

Presenter Information:

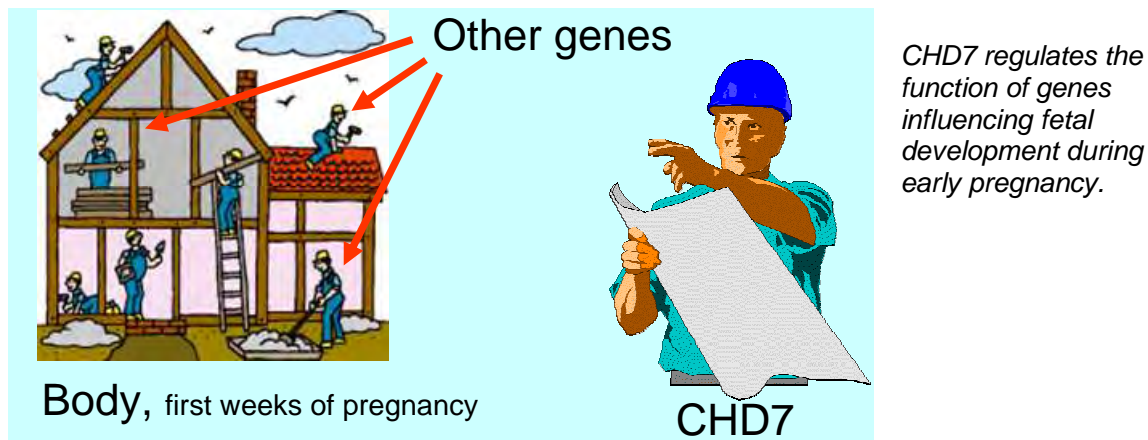
Nicole Corsten-Janssen studied medicine at the University of Groningen. She has been working in clinical genetics at the University Medical Center Groningen since 2008 and is currently in training to become a clinical geneticist. In 2009 she started her still ongoing PhD project that focuses on CHARGE syndrome, CHD7 and heart defects.

Professor Conny van Ravenswaaij studied medicine at the University of Leiden. In 1997 she was registered as a clinical geneticist. Her main interest has always been children with multiple congenital anomalies. Her group discovered the *CHD7* gene as major cause of CHARGE syndrome in 2004. In 2006 she changed affiliation to the University Medical Center Groningen, where she continued her multi-disciplinary outpatient clinic for CHARGE syndrome. She supervises studies in CHARGE syndrome, focusing on clinical variability and phenotype-genotype correlations, puberty development and smell, the role of CHD7 in heart development, Cochlear Implants and immune system and adrenal function.

Presentation Abstract:

CHARGE syndrome is a genetic disorder that is almost always caused by a mutation in the *CHD7* gene. We start our presentation with general information on chromosomes, DNA and gene, but we will focus on the genetics of CHARGE syndrome with special attention to the different genetic questions that parents asked us during the previous international CHARGE conferences. Like what is the CHD7 gene and what does it do? What are reasons to perform DNA analysis? What if no mutations are found with *CHD7* analysis? What is the recurrence risk of CHARGE syndrome for me or my child? Is *CHD7* the only gene causing CHARGE syndrome? We will save time for your personal genetic CHARGE questions.

All you want to know about CHARGE and genetics



How is CHD7 analysis done?

CHD7 analysis is performed on DNA. DNA is usually extracted from blood cells, but other tissues, e.g. skin or saliva, can also be used. Different types of mutations can be present in the *CHD7* gene. Most of these mutations will be detected by routine DNA analysis (called “sequencing”). Sometimes a part of the *CHD7* gene may be missing or even the whole gene (called a “deletion”). Deletions of *CHD7* are rare and occur in approximately 1% of CHARGE patients. They cannot be found by routine DNA analysis, but can be identified by other techniques (e.g. array, MLPA).

Type of mutations

Normal gene	Tim and his toy
Point mutation	Pim and his toy
Deletion	Tim and toy
Insertion	Tim and his big toy
Frameshift	Tim ndh ist oy

Why perform DNA analysis?

There are several reasons to perform DNA analysis:

- To provide certainty
- Confirm a tentative diagnosis in a child with atypical features (these two reasons have consequences for the clinical follow-up)
- Confirm the diagnosis, so that parents or siblings know their recurrence risk
- Prenatal options

What if no *CHD7* mutation is found in my child?

- A diagnosis of CHARGE syndrome can be made by identifying a *CHD7* mutation, or by looking at the clinical criteria for the syndrome. If your child fulfills the clinical criteria, he/she has CHARGE syndrome, irrespective of the results of *CHD7* analysis.
- Some other syndromes have clinical features that overlap with CHARGE syndrome and it is important to exclude these syndromes from the diagnosis.

- Current techniques are not good enough to identify all *CHD7* mutations.
- Other genes might also contribute to CHARGE syndrome (see below).

What is the risk that CHARGE syndrome will re-occur if we have another child?

Since familial CHARGE syndrome is extremely rare, the recurrence risk for parents who have a child with CHARGE syndrome is, in general, low. If parents want to learn more about their risk for future pregnancies, we recommend:

- A geneticist should see if the parents have any mild symptoms of CHARGE syndrome (hearing, balance, smell, shape of the ears).
- If a *CHD7* mutation has been found in a child, the parents can also be offered DNA analysis.

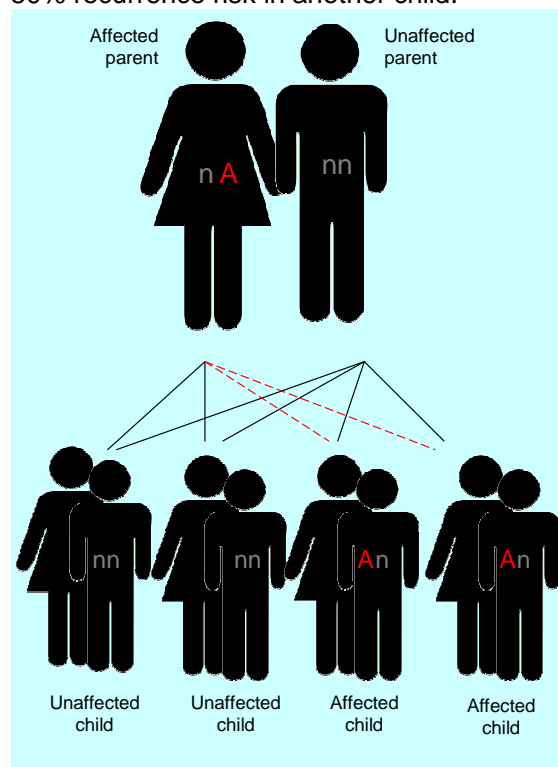
There are three possibilities:

1. Parent does not have CHARGE syndrome or a *CHD7* mutation

If the *CHD7* change is not found in one of the parents (the most common situation), there is still a small risk of carrying a *CHD7* mutation (“germline mosaicism”), so the recurrence risk is not zero, but 1% or 2%.

2. Parent has CHARGE syndrome

If one of the parents has CHARGE syndrome, the recurrence risk varies. Parents pass half of their genetic information on to their children. The parent with CHARGE syndrome can pass on either their normal *CHD7* gene or their gene with a mutation. This means that there is a 50% recurrence risk in another child.



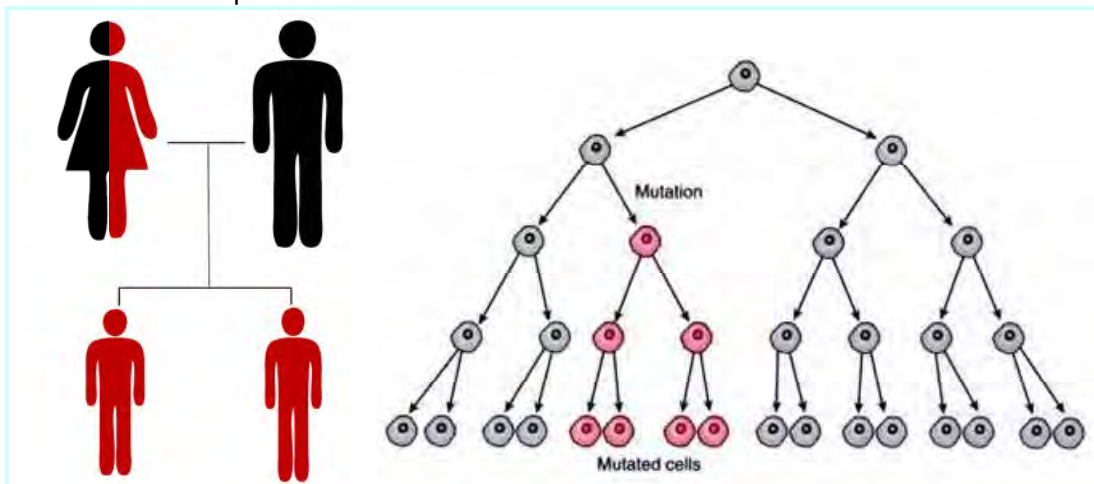
*The parent with mild CHARGE syndrome passes on the normal *CHD7* gene (n) or the abnormal *CHD7* gene (A). The recurrence risk is 50% for each pregnancy.*

3. Parent with a *CHD7* mutation in some of their cells (“mosaicism”)

Very rarely, a family may have two affected children with the same *CHD7* change, while the parents do not have any features of CHARGE syndrome. How can this happen? We may find that one of the parents carries a change in the *CHD7* gene in only some of his/her body cells. This is called mosaicism and it can occur when the fertilized egg has a normal *CHD7* gene, but a spontaneous change occurs later in one cell as the cells divide and grow (see

figure). Only the cells coming from that cell with the changed *CHD7* gene will have the mutation. If these cells are also present in the parent's ovaries or testes, egg or sperm cells with the *CHD7* mutation can be formed and lead to the pregnancy of a child with CHARGE syndrome.

If a parent has a mosaic form of the *CHD7* mutation, the recurrence risk for further children can be up to a maximum of 50%.



*In this example of mosaicism in the mother, there is a *CHD7* change (mutation) in some of her body cells. The scheme on the right shows that this can occur when the change (red cells) arises spontaneously during a cell division after fertilization. The mother will not have CHARGE syndrome herself, but she does have an increased risk of having affected children because she can pass on the *CHD7* change via an egg cell. The subsequent child will have the *CHD7* change in all its cells and will therefore have CHARGE syndrome.*

Options in a subsequent pregnancy

Parents who have a child with CHARGE syndrome in whom a *CHD7* mutation has been identified, may choose to have prenatal diagnosis performed for a subsequent pregnancy. But please remember that DNA analysis cannot predict the severity of CHARGE syndrome. A fetal ultrasound can provide extra information, like whether the baby has a heart defect, but ultrasound cannot “see” everything – deafness, developmental delay and behavioral problems cannot be detected.

The choice to have prenatal diagnosis is a personal one, and the geneticist must inform the parents well, so that they can make a choice they feel good about.

Is *CHD7* the only gene causing CHARGE syndrome?

In 5% to 10% of patients with typical CHARGE syndrome, no mutation in the *CHD7* gene can be found. This percentage is higher in patients who do not fulfill the clinical criteria for CHARGE syndrome (atypical presentation). So there may well be other genes that are also responsible for CHARGE or CHARGE-like syndrome. Mutations in a gene called *SEMA3E*, had been identified in two patients. A few other genes, like *CHD8* (a “candidate gene”), have been studied, but no mutations were found in these genes in CHARGE syndrome patients. Recently, we started to search for other genes that might cause CHARGE syndrome using a new technique, called next-generation sequencing or whole exome sequencing. This technique makes it is possible to look for mutations in all the known genes in a single test.

Any questions? Please come and ask us during the CHARGE conference, or send an email to n.corsten@umcg.nl or c.m.a.van.ravenswaaij@umcg.nl.

More information on our research projects on CHARGE syndrome is available at www.rug.nl/research/genetics/research/chargesyndrome/





Category (Medical/Genetics, Family Support, etc.)
(to be completed by Conference Chair)

Day
Breakout Session #(N): Time
Breakout location
(to be completed by Conference Chair)

Presentation Title

THE SCOOP ON POOP:
Is it really an art medium or fashion accessory?

Kate Beals, OTR/L and Elaine Sveen, Ed.S.

South Carolina Interagency Deaf-Blind Project
South Carolina School for the Deaf and the Blind
Spartanburg, SC, USA

Presenter information

Kate Beals is an Occupational Therapist with 16 years of experience working with children, not counting her 23 years as a single parent of a son who has autism. For the past five years she has worked with the South Carolina Interagency Deaf-Blind Project, providing training and support for the families and educational teams of children who have combined vision and hearing challenges, often with multiple and complex disabilities. After Kate spoke briefly about this topic at the 10th International CHARGE Syndrome Conference in Orlando, many parents requested a workshop devoted to this very fascinating subject.

Elaine Sveen is the Director of the South Carolina Interagency Deaf-Blind Project. Elaine has extensive training and experience in teaching and administration of programs designed for blind and visually impaired children, including those with multiple disabilities. She has worked in both mainstream programs as well as residential programs in Texas, Minnesota, Virginia, Maryland and South Carolina. She has served as president of two associations, the Association of Education and Rehabilitation for the Blind and Visually Impaired and the National Association of Parents for the Visually Impaired. She is the mother of four children, including a son who is blind.

Presentation Abstract:

Fecal smearing is one of the most stressful behaviors with which many parents of children with CHARGE Syndrome must cope. Since this topic is strictly taboo in Polite Society, parents have few opportunities to discuss their experiences, frustrations, and creative solutions related to this behavior. Given information about sensory processing differences in the Olfactory and Gustatory systems, parents will understand why fecal smearing is a far different experience for their children than for themselves.

11th International CHARGE Syndrome Conference
Scottsdale, AZ, USA July 25-28, 2013

The Scoop on Poop!



...Is it really an art medium?
...or a fashion accessory?



Kate Beals, OTR/L
SC Interagency Deaf-Blind Project



Elaine Sveen, Ed.S.
Director, SC Interagency Deaf-Blind Project

Rules

- First names only, please
- What happens in this session STAYS in this session – Respect one another's privacy and don't blab other folks' stories that don't belong to you without those folks' permission.
- **Caution:** This discussion is not suitable for children, nor is it suitable for uninitiated adults. Inappropriate language is likely to erupt at any moment, so brace yourself or move on while you can still get out discreetly.

Objectives

- Understand that children who have CHARGE Syndrome may process taste and smell differently from others
- Understand the impact these differences may have on the behavior of fecal smearing
- Increase awareness that you are Not Alone in coping with this challenging behavior.
- Learn – from one another and from the literature - positive coping mechanisms and effective strategies for clean-up and prevention.

Agenda

~ We will type up a session summary and make it available to you later ~

- Review structures and functions of the Taste and Smell systems, and differences occurring in CHARGE Syndrome
- Share experiences related to "IT"
- Does "IT" mean anything? (communication?)
- Discuss clean-up strategies – what has worked or not worked?
- Discuss prevention – what has worked or not worked?
- Discuss legal coping strategies & advice

That Poo You Do

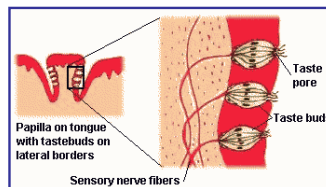


A
Revised
Bedtime
Story

by
Kate Beals
and
Jan Moore*


*Two sisters with time on their hands, free night and weekend minutes, and many years of graduate school to their credit...

Gustatory System - 4



We have almost 10,000 taste buds inside our mouths!
A single taste bud contains 50–100 taste cells representing all 5 taste sensations: salty, sour, sweet, bitter, and umami (savoriness).
Pathway: Facial, Glossopharyngeal and Vagus Nerves (Cranial Nerves VII, IX and X).

Taste in CHARGE



Differences

Three of the four cranial nerves most likely to be involved in CHARGE Syndrome affect taste:

VII. Facial:

- controls most facial expressions
- secretion of tears & saliva
- taste**

IX. Glossopharyngeal:

- taste**
- senses carotid blood pressure

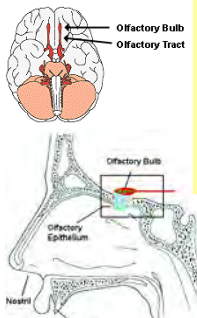
X. Vagus:


- senses aortic blood pressure
- slows heart rate
- stimulates digestive organs
- taste**

Functional Implications

- Good taste** is not a motivator
- Bad taste is not a deterrent**
- Limited exposure to taste due to g-tube feedings
- Oral defensiveness to texture is likely due to early g-tube feedings as well

Olfactory System - 5





OLFACTORY RECEPTOR NEURONS → **OLFACTORY BULB**

OLFACTORY BULB connects to:

- FRONTAL CORTEX** (Conscious perception of smell)
- HYPOTHALAMUS AMYGDALA** (Motivational and emotional aspects of smell)
- HIPPOCAMPUS** (Odor memory)

Pathway: Unlike the other senses, olfactory information goes straight to the frontal cortex of the brain without going through the thalamus first. It travels on the Olfactory Nerve (Cranial Nerve I).

Smell in CHARGE

Differences


- Anosmia (**inability to smell**) is a frequent feature of CHARGE Syndrome
- Structural differences – many are missing olfactory bulbs and stems
- Nasal blockages are common (bilateral choanal atresia)
- Cranial Nerve I (Olfactory)** involved in approx. 40%
- Study showed 100% correspondence between anosmia and problems with onset of puberty

Functional Implications


- What we think of as a “bad” smell **may not be aversive**
- Safety – can’t smell smoke from a fire, gas leak, spoiled food
- Social – unaware of body odors
- Smell is powerful - linked to memory, learning, and bonding – reduced access

Jorieke Bergman, MD, and Conny von Ravenswaaij-Arts, MD, PhD

Life in the Trenches



Does “IT” Mean Anything?



Grab a Bucket and Mop

WHAT WORKS?



WHAT DOESN'T?




An Ounce of Prevention

WHAT
WORKS?



WHAT
DOESN'T?

How do you cope?



Advice

As a parent of a child with CHARGE Syndrome, what is the best advice you have ever **been given**?



As a parent of a child with CHARGE Syndrome, what is the best advice **you would give** another parent?

Wrapping up...

**Thank you for coming,
and good luck to all!!!**

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*Evaluations,
please.*



Category: Education

Saturday
Breakout Session #5:24: 10:45-11:45
Palomino 6 & 7

“Peaking into the Future”: Expanding Opportunities to Achieve Desirable Outcomes When Students Transition from School to Adult Life

Wendy W. Bridgeo, M.Ed.
&
Erin Selke, B.S.

Deafblind Program
Perkins School for the Blind
Watertown, MA

Presenter Information: Wendy Bridgeo is a Vocational Teacher in the Deafblind Program at Perkins School for the Blind for over 30 years. She has been teaching career education, developing community-based vocational placements and supporting students and their families as they plan for transition from school to adult living/working. Wendy has extensive experience presenting to both national and international audiences on topics related to vocational training and portfolio development. She has collaborated with adult service providers with trainings specific to the needs of individuals with CHARGE Syndrome.
EMAIL: Wendy.Bridgeo@perkins.org

Erin Selke is a teacher in the Deafblind Program at Perkins School for the Blind. She attended Northeastern University where she studied Deaf Studies and elementary education. As a classroom teacher for the past five years, Erin has focused on teaching functional academics, vocational activities and community experiences. EMAIL: Erin.Selke@perkins.org

Presentation Abstract: This presentation will highlight the importance of providing students with CHARGE Syndrome including those with additional disabilities with a transition focused curriculum that starts with the end in mind. Discussion focuses on blending functional academics with the expanded core curriculum enriching career education and vocational training to increase opportunities and meaningful adult outcomes after school.

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“PEAKING INTO THE FUTURE”

EXPANDING OPPORTUNITIES TO ACHIEVE DESIRABLE
OUTCOMES WHEN STUDENTS TRANSITION
FROM SCHOOL TO ADULT LIFE

11TH INTERNATIONAL CHARGE SYNDROME CONFERENCE

Wendy W. Bridgeo, M.Ed.
Erin Selke, B.S.

Perkins School for the Blind
Deafblind Program
www.perkins.org
July 27, 2013

“PEAKING INTO THE FUTURE” WORKSHOP GOALS

- Provide families and educators with ways to assist their young adults in the transition process by blending functional academics with the expanded core curriculum and enriching vocational training to increase opportunities and prepare them for meaningful adult outcomes after school.



QUESTIONS TO CONSIDER

- What are the academics we use to function on a daily basis?
- What are the skills we need to succeed within the workplace?
- What are the functional skills that we use everyday and don't even realize it?
- What type of work would be realistic and motivating for my child/student?

DEFINITION OF FUNCTIONAL ACADEMICS

- What does functional academics mean?
 - Functional is defined as having a practical application and serving a useful purpose. Functional academics are real world applications of core academic content and related skills that are meaningful and relevant to an individual's present and future life.

• What does functional education mean for your child?

- Functional education does not mean that academic learning stops. It becomes more of an experiential process across many natural environments at school and in the community.
- When students learn through experience they are hands on and are able to see the entire process from start to finish. In most cases, students thrive when engaged in functional tasks because these experiences are rewarding and have meaning.

FUNCTIONAL ACADEMICS

Each category includes skills needed by individuals to develop maximum independence in living and working environments. Skills are hierarchically arranged by level of complexity.

Functional skills focus on different categories such as:

- Domestic
- Vocational
- Recreational and Leisure
- Community

Tom Miller, Educational Partnerships

EXPANDED CORE CURRICULUM

The Expanded Core Curriculum is an initiative that defines the scope of learning experiences and skills required for students with sensory impairments. It includes nine skill categories that are not part of standard general education academic or special education curricula that includes:

- Sensory Efficiency
- Compensatory Skills
- Assistive Technology
- Social Interaction
- Orientation and Mobility
- Independent Living
- Recreational and Leisure
- Career Education
- Self Determination

Partnerships

Tom Miller, Educational

FUNCTIONAL ACADEMICS AND EXPANDED CORE CURRICULUM

For learners with sensory impairments and additional disabilities a Functional Curriculum that includes the Expanded Core Curriculum is vital to increasing opportunities to develop self awareness, increased ability to make informed decisions, practice problem solving, community participation and have a voice in planning their future as young adults.

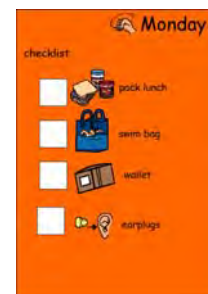
FUNCTIONAL READING IN THE COMMUNITY



FUNCTIONAL LANGUAGE ARTS (READING AND WRITING)

Reading

- Creating a calendar
- Following a daily schedule
- Creating a shopping list
- Checklists
- Labeling pictures
- Social stories
- Recipes
- Symbol boards
- New2you articles



FUNCTIONAL LANGUAGE ARTS (READING AND WRITING)



FUNCTIONAL LANGUAGE ARTS (READING AND WRITING)



Writing

- Printing your name
- Writing your signature
- Voting on preference
- Using a word bank
- Email or letter
- Journal
- Time sheet
- Shopping list
- Using a sentence starter (I want....)
- Assistive tech writing programs (Clicker 6)

TO EVERY CHILD READING CAN HAVE A
DIFFERENT PURPOSE...

Reading symbols to
assemble a photo button.



Voting: what to cook?



FUNCTIONAL MATH – REAL LIFE IN SCHOOL

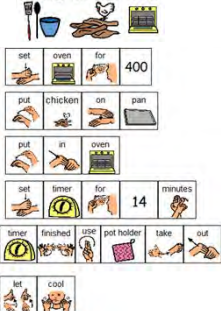
Classroom

- Corresponding numbers to items
- Using a calculator
- Counting people and objects
- Estimating
- Making change
- Matching amounts
- Measuring
- Using a scale
- Packaging jobs
- Temperature and weather



FUNCTIONAL MATH – REAL LIFE

cooking chicken oven



Cooking

- Identifying measuring amounts
- Recipes
- Identifying time and temperature
- Identifying correct size bowl and pan
- Use of small appliances (toaster oven, microwave)
- Weight
- Portioning

FUNCTIONAL MATH

Money

- Understands the value of money
- Handles money appropriately
- Identifies coins and bills
- Work for pay
- Using a calculator
- Sorting and rolling coins
- Managing a wallet
- Making simple purchases
- Cashing a pay check
- Bundling bills



FUNCTIONAL MATH

Time

- Reading a clock
- Using a watch
- Sets and responds to a timer
- Follows a schedule
- Time management
- Prioritize responsibilities
- Understanding increments



FUNCTIONAL MATH IN THE COMMUNITY



- Learning the concept of earning money to make purchases
- Learning to complete a transaction.
 - Using their own mode of communication
 - Using and managing a wallet
 - Using the "round up" dollar method.
- Understanding the exchange of money
- Using self-serve, debit card, or cashier
- Making purchase from vending machines
- Responsible for your purchase

FUNCTIONAL MATH IN THE COMMUNITY

Community

- Simple purchases
- Recognizing prices
- Understanding sales and discounts
- Using the “rounding up” method
- Using an ATM/debit card
- Paying at a restaurant
- Estimating costs



SOCIAL SKILLS

- When in the work place often social skills are just as - if not more important - than production.

- Introducing yourself
- Greetings and closings
- Turn taking
- Choice making
- Encourage problem solving
- Appropriate behavior
- Appropriate social interactions
- Creating opportunities to think of others
- Expectations and consistency



SOCIAL SKILLS

- Communication is essential to everyday life. often struggle with the social skills to appropriately interact with others.
- Social interactions
 - Encourages self-esteem
 - Creates friendships
 - Provides opportunities to engage with others
 - Builds positive relationships
 - Helps them feel connected within environments
 - Provides opportunities to self advocate
 - Allows them to become integrated within community
 - Provides opportunities to work on reading, writing and math skills

SOCIAL SKILLS – “LUNCH BUNCH”



WHAT DOES THE CURRICULUM OF A FUNCTIONAL TRANSITION CONTAIN?

- Functional Academics
- Vocational Exploration
- Assessment
- Career Education Classes
- Vocational Training
- Transition Planning

FUNCTIONAL ACADEMICS IN THE WORK ENVIRONMENT

Canine Catering: making dog biscuits for sale.

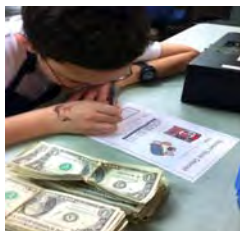


Using a scale to weigh and price candy at work.

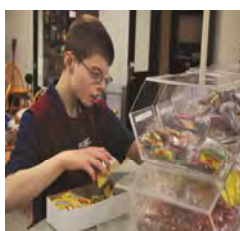


FUNCTIONAL ACADEMICS IN THE WORK ENVIRONMENT

Counting money and
completing a deposit slip.



Filling snack bins at
Student Store.



FUNCTIONAL ACADEMICS IN THE WORK ENVIRONMENT

Dome magnifier to view
product codes at work.



Using employee card to
sign in at work.



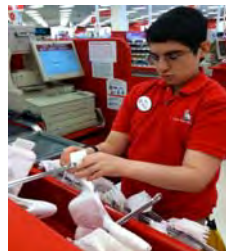
BEGIN WITH THE END IN MIND...

STEVEN COVEY

Career Education class:
at age 14 his dream to
work at Target.



Age 21, supported
employment at Target.



THE VALUE OF WORK

“Tell me and I'll forget;
show me and I may remember;
involve me and I'll understand.”

Confucius 450 BC

“PEAKING INTO THE FUTURE”



IT IS OUR JOB TO CONNECT ...



THANK YOU!!!

Wendy.bridgeo@perkins.org

Erin.selke@perkins.org



Category: Education

Saturday
Breakout Session #5:25: 10:45-11:45
Palomino 8 & 9

**Preschoolers Tomorrow's
Teenagers: Bridging the Gap**

Marguerite Bilms M.Ed Teacher
Sharon Stelzer, M.Ed Teacher
Martha Majors, M.Ed Assistant
Education Director
Deafblind Program
Perkins School for the Blind

Presenter Information:

Marguerite Bilms has been working with individuals who are deafblind for the past 18 years. She received her Master's of Education Degree from Boston College, in Severe Special Education with a concentration in Deafblindness, and was nominated as a Helen Keller Fellow. Marguerite has been a Teacher within the Deafblind Pre-School at Perkins School for the Blind for the past three years, and prior to working at Perkins, she was an active volunteer and intern at the Helen Keller National Center in Sands Point, New York.

Sharon Stelzer has been a teacher in the Deafblind Department at Perkins School for the Blind for the past twenty eight years. She has done numerous trainings/presentations nationally and internationally. She has been teaching students with CHARGE Syndrome for more than twenty years. She currently teaches adolescents with CHARGE Syndrome. She has developed a webcast related to teaching strategies for children with CHARGE Syndrome.

Martha M. Majors, Assistant Education Director, graduate degrees in special education with a specialization in Deafblind Education and Intensive Special Needs from Boston College and Northeastern University; former adjunct faculty member at Boston College and University of Massachusetts. Martha has worked in the Deafblind Program at Perkins School for the Blind for almost 40 years. She has extensive experience in developing innovative educational programs for learners who are deafblind both nationally and internationally. She enjoys developing curriculum for learners who are deafblind. As a consultant for the Perkins International Program she continues to share her expertise in developing countries. She has been an advocate for learners with CHARGE Syndrome for more than 25 years. She recently developed a webcast related to CHARGE Syndrome and is an active participant and presenter at the CHARGE Foundation International Conference.

Presentation Abstract:

This presentation discusses observations based on the educational development of children with CHARGE Syndrome as they progress from preschool education through secondary programming.

Young school-age students with CHARGE require predictability and consistency in relation to the development of communication, sensory and teaching strategies as well as curriculum. As these students progress from a preschool curriculum to a secondary curriculum, their need for a variety of strategies including sensory and educational continue to be vital. This presentation will discuss what these strategies may look like from preschool to adolescence.

3rd Professional Day & 11th International CHARGE Syndrome Conference
Fairmont Scottsdale Princess Hotel, Scottsdale, AZ July 25-28, 2013

CHARGE Conference July 2013

Preschoolers: Tomorrow's Teenagers-Educational Strategies that Bridge the Gap

Marguerite Bilms, M.Ed.
Martha Majors, M.Ed.
Sharon Stelzer, M.Ed.
Perkins School for the Blind
Deafblind Program

Program Components for Students with CHARGE

- LANGUAGE AND COMMUNICATION
 - Use of Total Communication
 - Supports to use Speech
 - Supports to use Sign language
- CURRICULUM
 - Must include **teaching strategies** that are effective for students with CHARGE Syndrome

Accommodations to Support Access to the CURRICULUM that is FLEXIBLE

- Supportive Environments that include
- Communication
- Vision and Fatigue related to use of Vision
- Hearing and access to information
- Cognition and adapted content as needed
- Motor (both fine & gross motor)
- Sensory and Sensory Breaks

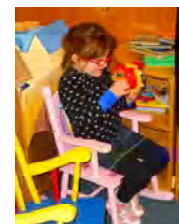
What Students with CHARGE Syndrome Should Learn

- How to be an effective communicator
- How to be social
- How to be part of a group

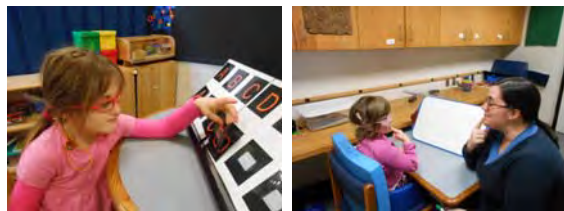
Preschool: Frequently Used Teaching Strategies

- Choice Making
- Negotiation
- Clear Expectations
- Clear Beginning-Middle-End
- Behavioral Strategies

Curriculum: Pre-School Play & Cognition



Curriculum: Pre-School
Language & Communication



Curriculum: Pre-School
Sensory Integration



Curriculum: Pre-School
Social Development



Curriculum: Pre-School
Self-Help Skills



Teaching Strategies

Beginning-Middle-End	Choice Making	Organizational Skills
Partial vs. Full Participation	Task Analysis	Prompt Levels
Motivation	Clear Expectations	Active vs. Passive Learning
Follow Student's Interest	Needs Board	People Preferences
Signals (verbal, auditory, visual)	Pause time for response	Structure and Routine

VI. Teaching Strategies
Pre-School

Beginning-middle-end	Choice Making	Organizational Skills	Partial vs. Full Participation	Structure and Routine
Prompt Levels	Motivation	Clear Expectations	Follow Student's Interest	Pause time For response

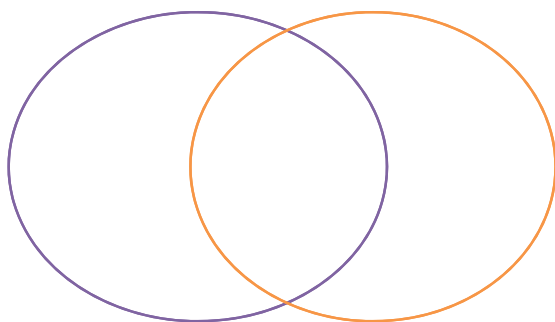
Functional Academics (Teenager): Frequently Used Teaching Strategies

- Negotiation
- Structure & Routine
- Following Student's Lead
- Choice Making
- Clear Beginning-Middle-End
- Teaching in Natural Environments
- Behavioral Strategies (environmental management, etc.)

Similarities in Teaching Strategies

- Negotiation
- Choice Making
- Behavioral Strategies

Today's Pre-Schoolers, Tomorrow's Teenagers



Implications of Similar Teaching Strategies

- Students' needs for strategies are "Life long"
- Starting young can provide time to "practice" skills
- Skills can develop and mature over time
- Provides structure early on that can be a life long tool
- Provides consistency throughout all environments

Questions & Wrap-Up



Contact Information

- Marguerite.Bilms@perkins.org
- Martha.Majors@perkins.org
- Sharon.Stelzer@perkins.org



Category: Family Support, Adult

Saturday
Breakout Session #5:26: 10:45-11:45
Palomino 10

Planning for the Day After:
Developing Your Unique Special Needs
Lifetime Care Plan


Steven C. Rhatigan, Principal
Archer Consulting Group LLC

Presenter Information:

Steve has been in the insurance and estate planning profession since 1978. In the early 80's, he began working with the special needs community and soon became an enthusiastic disability advocate and helped build the national organization Estate Planning for Persons with Disabilities and was a founding member of the National Institute for Life Planning. His initial efforts, in conjunction with several like-minded planners, laid the foundation for many of the current techniques used in the field of special needs planning today. Although his primary passion is working with uniquely challenged individuals, and their caregivers, he also advises a wide range of groups in an effort to pass on the knowledge and experience accumulated through thousands of interactions with the extraordinary people he has had the privilege to know and serve. For more than 32 years, the Archer Consulting Group has worked to make this a better world for persons with unique lifetime care needs and their families. We partner with families to design, implement and manage plans that benefit our clients, give peace of mind and confidence to their caregivers and help them navigate life with confidence.

Presentation Abstract:

Caring for a loved one with unique needs can be confusing and frustrating. Taking the guesswork out of life's most difficult challenges and putting your family on a path to a secure future requires an integrated and dynamic strategy. We will identify and discuss the key interrelated planning strategies you need to utilize if you want to assure them of the required care throughout their lifetime.




Archer Consulting Group
Financial, Legal and Lifetime Care Strategies

Building a Firm Foundation:
Developing Your Unique Special Needs Lifetime Care Plan

Presenter: Steven C. Rhatigan, Principal

Tuesday, July 09, 2013

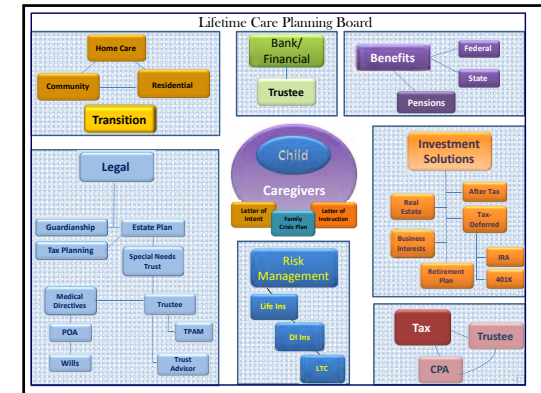

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1054 Canal Blvd • Suite 2 • The Woodlands, TX 77380 • 281.227.4019 Main



The Archer Consulting System

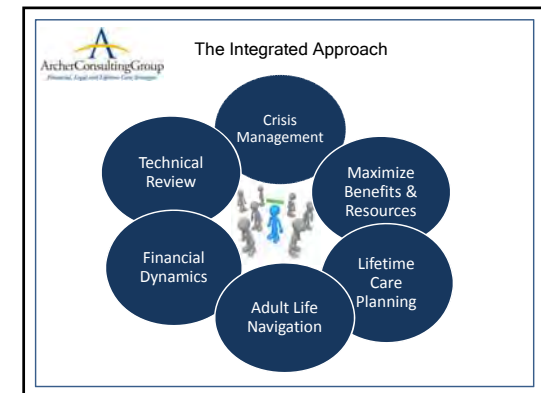
At Archer Consulting, we design, implement and manage lifetime care plans for people with unique needs. We carefully coordinate each person's legal, medical, financial, governmental, vocational, residential and educational requirements into a rational and viable plan. This unified approach eliminates much of the frustration so many families encounter when caring for a person with lifetime care needs, and assures that their loved ones receive access to the level of services they deserve **for a lifetime.**

Notification
Archer Consulting Group, LLC, does not offer legal advice or services. No one here is an attorney, nor is anyone likely to become one. None of the following information is intended to replace, supplant, usurp, supersede, or in any way cause your attorney to become aggravated by its contents. We merely wish to provide you with good information and the motivation to use it properly in your planning efforts.

The Major Issues

- Residential Arrangement
 - Where will he or she live now and in the future?
- Continuity of care and supervision
 - Who can do the things I do to provide the needed support?
- Getting and Maintaining Benefits
 - How do we find, qualify and keep benefits in place?
- Budgeting & Funding for the future; theirs and ours?
 - How much is needed? Who will manage it?
- Does my plan have a heart?
 - The Letter of Intent



ArcherConsultingGroup
Financial, Legal and Lifetime Care Strategists

The Integrated Approach

⊕ In **life**, crises will arise.... it's how you respond that can make **all the difference** in the outcome.

Crisis Management

⊕ Issues

- ❑ The "Daily" Report
- ❑ The Emergency Guide
- ❑ The "First Responder" Drill
- ❑ The Letter of Intent


ArcherConsultingGroup
Financial, Legal and Lifetime Care Strategists

The Integrated Approach


⊕ Who is entitled to benefits?

- ⊕ Which
- ⊕ When & Where
- ⊕ How & How Much

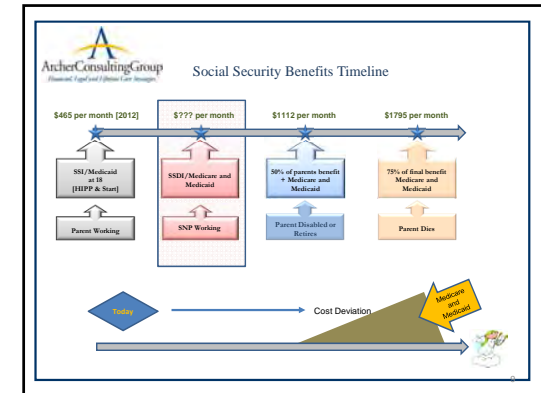
Maximize Benefits & Resources



State Benefits (Programs)
Medicaid/Waivers
CBA
CLASS
HCS
CHIP



Federal Benefits (Cash & Medical)
SSI
SSDI
Medicaid
Medicare
VA



ArcherConsultingGroup
Financial, Legal and Lifetime Care Strategists

The Integrated Approach

⊕ It's difficult to think and plan beyond tomorrow when you are juggling the needs of today.

Lifetime Care Planning

The Care Plan

- What are the unique supports your child requires today?
- What are the future support needs?

The primary goal of a comprehensive special needs plan is to ensure that adequate funding is provided to replace the unique supports you currently supply for free.

⊕ Issues

- ❑ Think and Plan in Segmented Time Periods
- ❑ Be Real
- ❑ Define Your Goals and Expectations
- ❑ Understand Your Value as Caregiver
- ❑ The Letter of Intent

ArcherConsultingGroup
Financial, Legal and Lifetime Care Strategists

The Integrated Approach

⊕ Your "child" will grow up!

⊕ What you do today will fundamentally determine positive outcomes in the future.

Adult Life Navigation

⊕ Issues

- ❑ Time-based Issues
- ❑ Reasonable -- *non emotional* -- Expectations
- ❑ Test Alternative Care Options
- ❑ The Letter of Intent



Archer Consulting Group
Financial, Legal and Lifetime Care Strategies

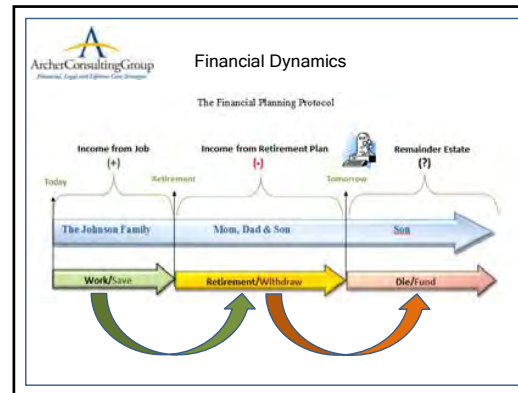
The Integrated Approach

Financial Dynamics

- How much is needed to care for my special needs person now and in the future?
- Is my financial plan structured to secure their future?

Issues

- The "Living" Costs
- The "Lifetime Care" Plan Costs
- Don't Forget the Tax Deductions



Archer Consulting Group
Financial, Legal and Lifetime Care Strategies

Financial Dynamics

Summary of Survivor Needs Analysis

Summary Page 1
Date: 06/10/2013

Presented By: Steven C. Rhoades

	First Year	Total for All Years
Financial Goals		
Direct Care Expenses	37,260	5,706,700
Personal Expenses	3,000	342,156
CarePlan Management	6,000	804,367
Trust Management	12,625	965,738
Total Financial Goals	58,885	\$7,778,961
Expected Assets/Benefits		
RGDI-Survivor Benefit	22,344	2,932,200
Total Expected Assets/Benefits	\$22,344	\$2,932,200

PV \$1.3M

Archer Consulting Group
Financial, Legal and Lifetime Care Strategies

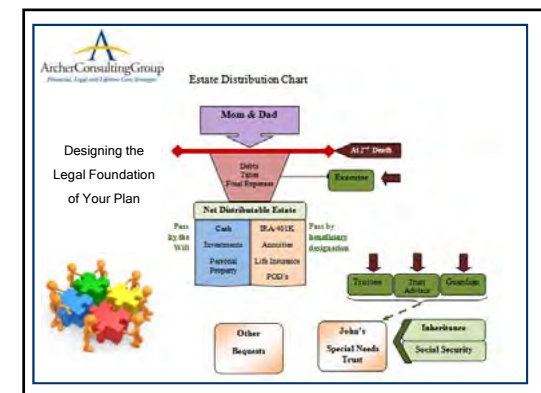
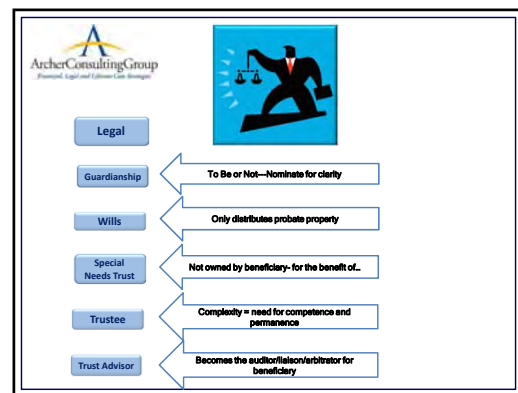
The Integrated Approach

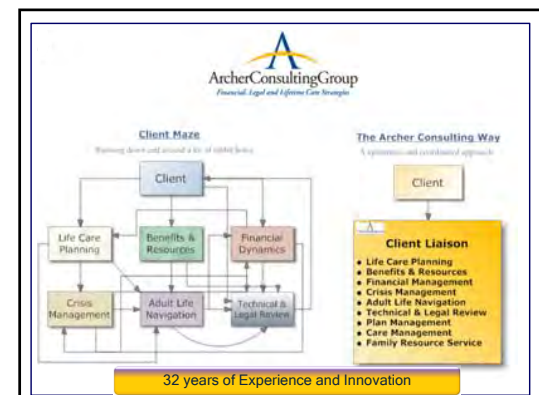
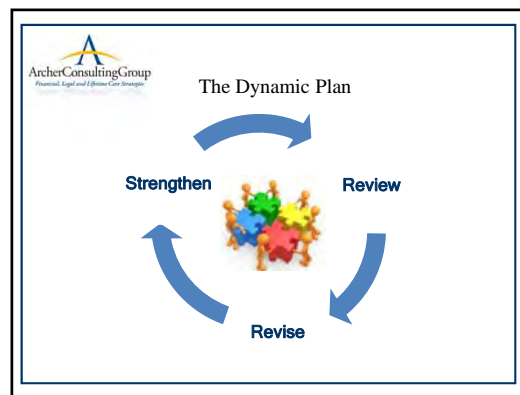
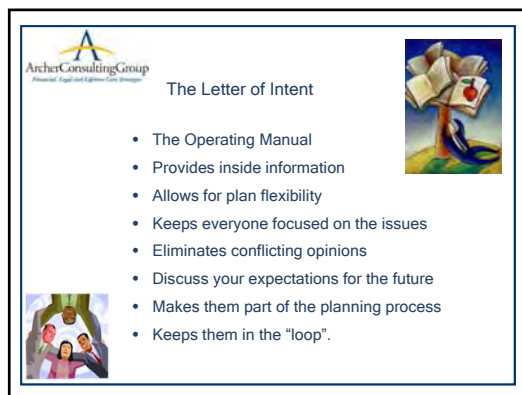
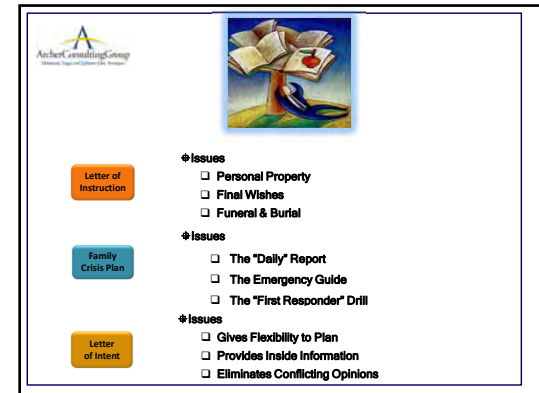
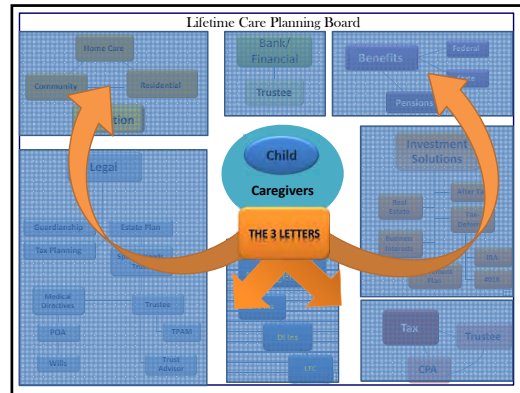
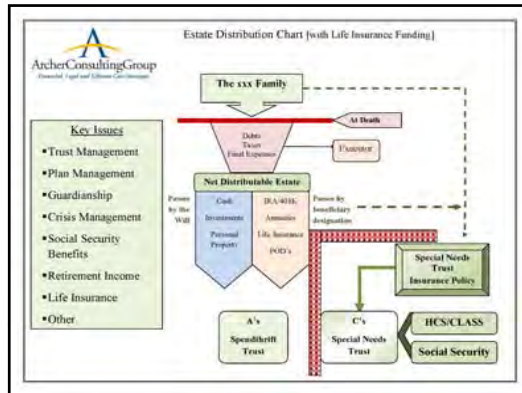
Technical Review

Are all of your:

- Legal Strategies
- Financial & Care Plans
- Benefit Programs
- Intentions

...working in harmony?







Archer Consulting Group
Financial, Legal and Life Insurance Case Strategies

If You Need A Little Guidance --



Action Step

☒ Call for a no obligation meeting at our offices.

We will spend an hour or so, at no cost, to listen to your unique story to better understand your goals and needs.

You will also have the opportunity to be fully briefed on the extent of our services and how we might work with you to design, implement and maintain your lifetime care plan.

We will provide you with all the information required to make an educated decision on your next steps.

1717 St. James Place ■ Suite 205 ■ Houston, Texas 77056 ■ 713.572.1717 Main
1054 Canal Blvd ■ Suite 2 ■ Thibodaux, LA 70301 ■ 985.227.4019 Main



Category: Parent Share
Behavior

Saturday
Breakout Session #5:27: 10:45-11:45
Dorado

“Parent Share”
Behavior

Betsy Bixler, M.Ed.
Deafblind Education
Perkins Training Center
Perkins School for the Blind
Watertown, MA 02472

Presenter Information:

Betsy is currently the Manager of Perkins Training Center, a professional development and continuing education program that provides lectures, workshops and courses to professionals and family members working with and on behalf of students with visual impairment and deafblindness. Included in the training plan conducted by the Perkins Training Center, are workshops and lectures that address critical topics that impact children with CHARGE syndrome.

Presentation Abstract:

This is the first of four facilitated sessions conducted for parents, each with an individual focus on the topics of: Behavior, Education, Adult Services and Medical.



Category: Education

Saturday
Breakout Session #6:28: 1:00-2:00
Palomino 1 & 2

**Technology for Learning,
Literacy and Fun**

Holly Cooper
Deafblind Educational Consultant
Texas School for the Blind
and Visually Impaired

Presenter Information:

Holly Cooper was a classroom teacher of students with multiple disabilities and later an itinerant teacher of students with visual impairments, including deafblindness. She joined Texas School for the Blind and Visually Impaired Outreach program in 2001 as an assistive technology consultant, and in 2006 joined the deafblind team as an educational and assistive technology consultant. She travels the state of Texas supporting students with deafblindness, their teachers and families. Holly has a special interest in CHARGE syndrome, assistive technology and teacher preparation. She has also done adjunct teaching for Texas Tech University in visual impairment and deafblindness.

Presentation Abstract:

This presentation will be an overview of assistive technology and computer applications which are both fun and useful in the home or classroom. It will include a discussion of assistive technology with an emphasis on low vision accessibility, and accessibility for users with severe disabilities. It will include a brief overview of computer low vision accessibility settings and applications, magnification devices, alternative input devices, electronic book readers. Voice output switches and medium-tech augmentative communication devices will also be discussed. Audience participation will be invited for participants to do a show and tell of iPad apps which they like using with children and youth with CHARGE.

Technology for Learning and Fun: Using Assistive Technology in the Home and Classroom

Holly Cooper, Ph.D.

Deafblind specialist, Texas Deafblind Project
Texas School for the Blind and Visually Impaired (retired)

Using Technology

It's not about what cool products are out there,
It's about what your son or daughter wants and needs to do.

What are some good uses of tech? In the classroom we use these devices, they may also be appropriate for your child to use at home:

- Vision magnification technology
- Amplification technology
- Computer assisted learning
- Internet use for research and learning
- Augmentative Communication devices
- Electronic books
- Assistive devices for daily living activities
- Hobbies and entertainment

Computer Use

A large monitor is a good thing, but there are other, sometimes better options.

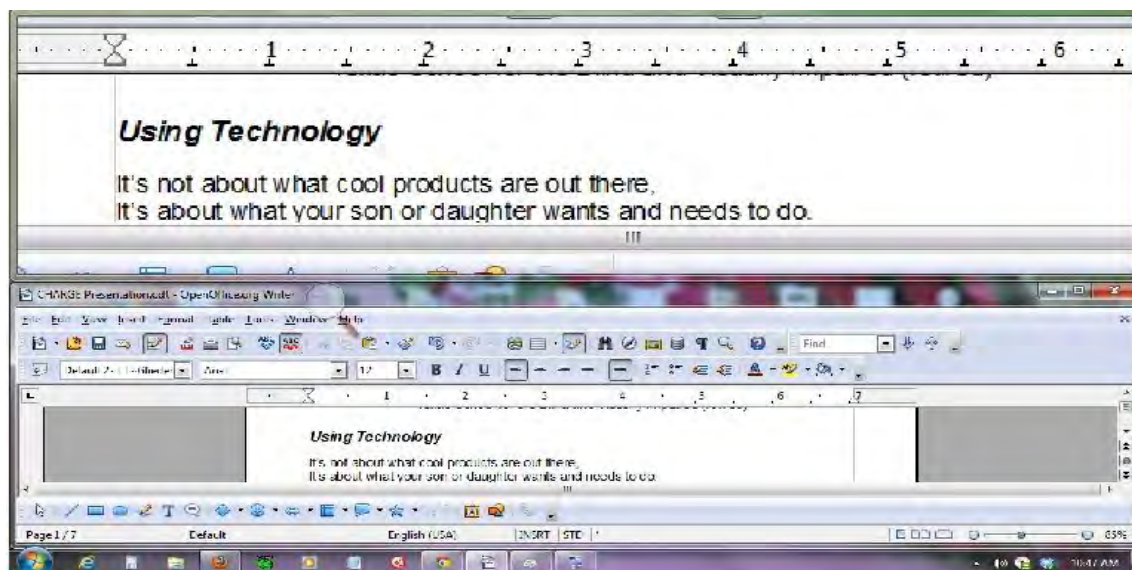
- Built-in magnification and accessibility features
- Add-on software to magnify the screen image
- Easy key commands
- Computer Magnification
- Windows and Mac have accessibility and magnification features.

Accessibility features make the icons, menus, text size and other controls larger

Magnification makes a selected area larger, but the user must scroll to see all areas of the screen.

Computer Magnification

Windows showing built-in magnification of a webpage.

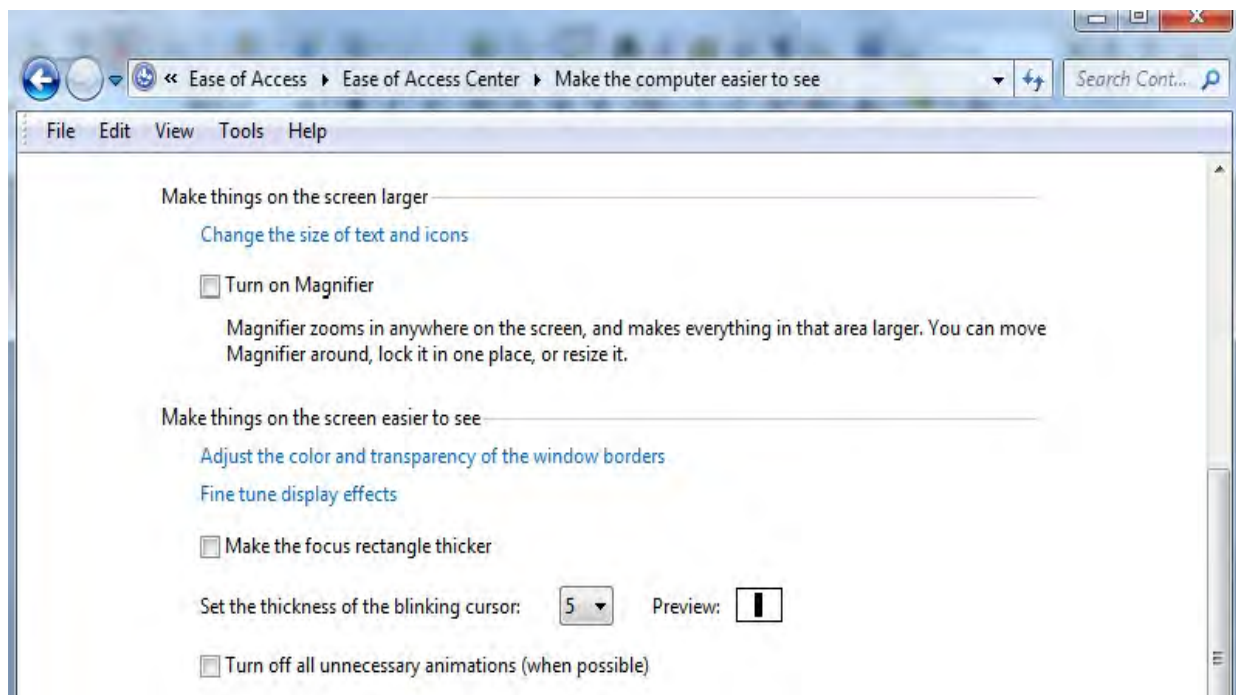


Top half of screen is magnified

Bottom half of screen is the standard view

This can be confusing to inexperienced users!

Other vision accessibility features are also available in Windows and Mac OS

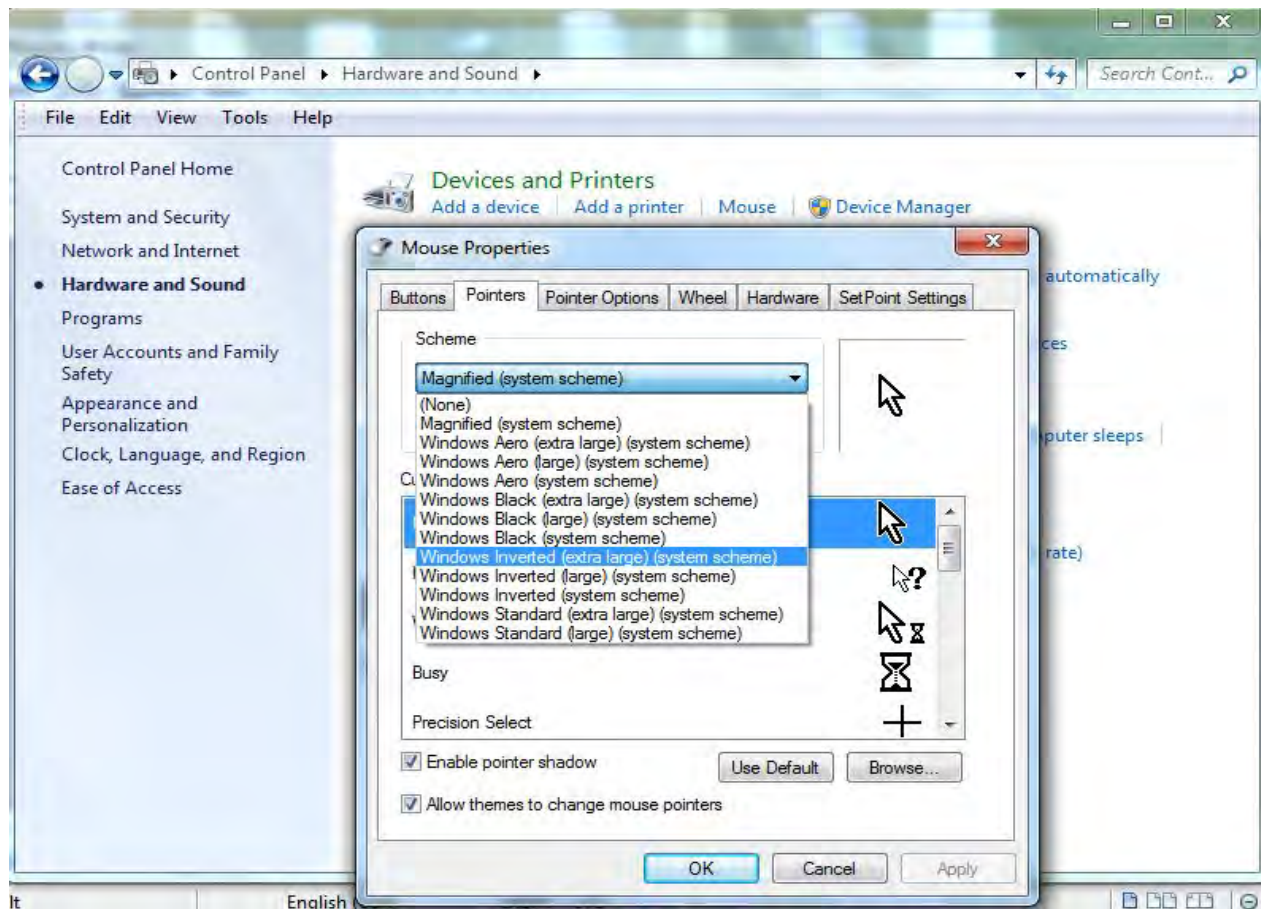


Keyboard Controls

When using an internet browser, users can make the print size larger by Holding down the “Ctrl” key and pressing “+” “Ctrl” and -

Mouse Pointer

Sometimes just making the mouse pointer larger can be helpful. In windows, find the control panel, and select”, then “mouse properties” and “pointers” Some free customizable mouse pointers are available



Screen Magnification Software

For users who are using the computer at a middle or high school grade level for research or learning applications, screen magnification software may be the best choice.

ZoomText

www.aisquared.com

Magic

www.freedomscientific.com

Supernova Magnifier

www.yourdolphin.com

Touch Screen

For younger users, or those who are less academic, a touch screen can make a computer much easier and more understandable.

Touch screen tablets such as the iPad are very popular with young people with disabilities, but don't exclude knowledge about a full featured computer from your child's educational experiences.

Adapted Input Devices

Keyboard and mouse alternatives:

Zoomcaps stickers for a standard keyboard, track balls,

etc. www.infogrip.com

Big keys: www.bigkeys.com

Intellitools keypad: www.intellitools.com



Tablet Computers

Tablet computers are light and portable and can be handy for games, web browsing, reading ebooks, email and texting:

iPad 2

Tablet PC's

Android tables

Electronic book readers

Ebook readers such as the:

Kindle

Nook



Allow text size adjustment for large print options

Kindle Paperwhite is backlit and is easier to see in bright light such as outdoors

Kindle has long battery life

Nook and others have a backlit screen, color display

Electronic book readers use special files known as ePub

Free file converters are available

A textbook on CD in a .pdf format can be loaded on most ebook readers from a computer

Magnifiers

Optical magnifiers

Video magnifiers

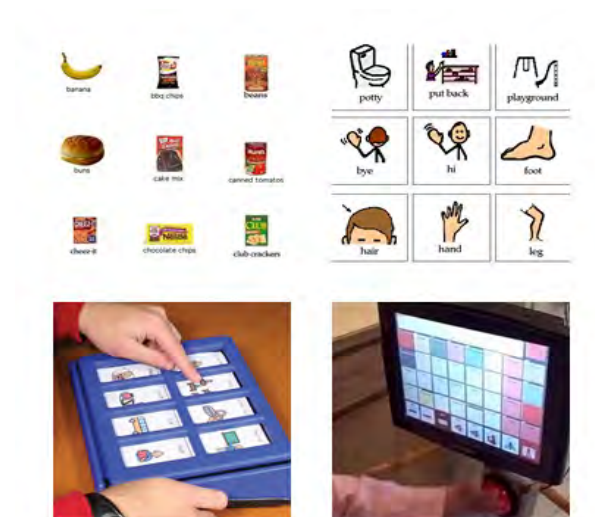


Amplification

FM amplification
Sound field generators
Audio input alternatives to headphones

Communication

Picture symbol displays
Talking switches
Voice output switch activated devices



Dynamic display augmentative communication devices

www.enablingdevices.com

www.ablenetinc.com

www.dynavoxtech.com

www.rjcooper.com

Communication

An inexpensive solutions for communication needs

Proloquo2Go software for use on an iTouch or iPad

www.proloquo2go.com

Sounding Board from Ablenet

<http://www.ablenetinc.com/Assistive-Technology/Mobile-Device-Access/SoundingBoard>

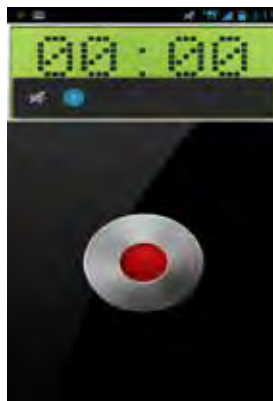
Tap to Talk

<http://www.taptotalk.com>

Sharing and Social Use of Technology

Computers can be used to share experiences, build functional literacy skills and have fun.

PowerPoint presentations can be created with added voice, video clips with sign language, and switch accessibility option.



Scrapbooking Software can be an easy and fun way to embellish photos, keep picture journals and share stories.

My Memories Suite www.mymemories.com

Memory Mixer www.memorymixer.com

Digital Scrapbook Artist www.daisytrail.com

When appropriately supervised

Facebook
Text messaging
Instant messaging via the computer

Can be good ways to support functional use
of literacy and age-appropriate social
communication

Video phone calls using

FaceTime on the iPhone : <http://www.apple.com/iphone/features/facetime.html>

Skype : <http://www.skype.com/intl/en-us/features/allfeatures/video-call/>



Category: Medical

Saturday
Breakout Session #6:29: 1:00-2:00
Palomino 3

**NEUROLOGICAL AND
DEVELOPMENTAL ASPECTS OF
CHARGE SYNDROME**

Dr. Jules Constantinou, MD FRACP

Center for Autism & Developmental Delay
& the Comprehensive Epilepsy Program

Henry Ford Health System

Presenter Information:

Dr. Jules Constantinou is Director of Pediatric Neurology at the Center for Autism and Developmental Delay and the Comprehensive Epilepsy Program in the Henry Ford Health System in Detroit. He completed Neurology Residency in Australia where he worked with Dr. George Williams, well known to the CHARGE community, and Neurology Fellowship at Boston Children's Hospital.

Presentation Abstract:

Cranial nerve impairments affecting smell, vision, facial movement, hearing, balance and swallowing are integral to CHARGE syndrome. Structural brain anomalies such as cortical dysgenesis, agenesis of the corpus callosum, hydrocephalus occur less frequently. This neurologic primer will explore the underpinnings of the developmental and motor delays, the feeding issues and the behavioral challenges and the repetitive behaviors which so frequently accompany the syndrome. Similarities to attention deficit hyperactivity disorder, obsessive-compulsive disorder, tic disorder and the autistic spectrum will be highlighted. Issues related to seizure disorder will be discussed.

A relaxed and interactive forum with time for questions and answers is planned.



Category: Medical/Genetics

Saturday
Breakout Session #6:30: 1:00-2:00
Palomino 4 & 5

**Bone Health...NOT a
Humerus Issue**

Kim Blake

Professor of Pediatrics
IWK Health Centre
Halifax, Nova Scotia, Canada

Jeremy Kirk

Consultant Pediatric Endocrinologist
Diana Princess of Wales Children's Hospital
Birmingham UK

Presenter Information:

Dr. Kim Blake is a Professor of Pediatrics at the IWK Health Centre in Halifax, Nova Scotia, Canada. She began her involvement with CHARGE 30 years ago at Great Ormond Street hospital in the UK. She published some of the earliest papers of CHARGE Syndrome and helped organize the UK family support group. At Dalhousie University in Halifax, she has continued her research on CHARGE, with focus on anesthesia, feeding, sleep and issues of the adolescent and adult with CHARGE. Kim has recruited local faculty and mentored many medical students in doing research on CHARGE Syndrome.

Dr. Jeremy Kirk is a Medical Advisor and Committee member UK CHARGE Family Support group. He is a Consultant pediatric endocrinologist (Honorary Reader) at the Diana Princess of Wales Children's Hospital in Birmingham UK, with a special interest in hormonal problems including growth hormone therapy and puberty, and has published on these, including chapters in both the German and American books on CHARGE Syndrome. Dr. Kirk also set up UK screening for the CHARGE gene CHD7 in Birmingham. He is currently setting up a national UK survey of CHARGE Syndrome through the Royal College of Paediatrics and Child Health (RCPCH) and is also working with Great Ormond Street and Manchester Children's Hospital to set up a network of national specialist CHARGE clinics.

Presentation Abstract:

Children with CHARGE syndrome have a number of risk factors that predispose them to poor bone health (Osteoporosis). Firstly the nutrition concerns that often starts in early childhood. Secondly, activities that are weight bearing are a challenge, and finally delayed puberty. This presentation will cover all of the above issues and will cite personal data collections from both authors to offer recommended treatments.

3rd Professional Day & 11th International CHARGE Syndrome Conference
Fairmont Scottsdale Princess Hotel, Scottsdale, AZ July 25-28, 2013



Category: Family Support

Saturday
Breakout Session #6:31: 1:00-2:00
Palomino 6 & 7

Resilient Parenting

Tim Hartshorne, Ph.D.
Central Michigan University

Presenter Information:

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. He has been researching and presenting about CHARGE syndrome since 1993, motivated by the birth of his son with CHARGE in 1989. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. He is first editor of the book *CHARGE Syndrome*.

Presentation Abstract:

Parents of children with CHARGE often have moments when they feel inadequate to the task of raising their child. While other parents seem to have what it takes, they become discouraged about their own abilities. This presentation addresses how parents develop resilience in parenting their child with CHARGE. Parents come to recognize that life can have meaning, and that they can develop the courage to be imperfect, and that they can courageously raise their child.

Resilient Parenting

Tim Hartshorne, proud parent



Everyone else seems competent

- AND
 - Happy with their child and family
 - Able to stand up to professionals and the schools
 - On top of the medical issues with a huge vocabulary
 - Able to still have a life

“Tonight I am so very tired of being the person figuring out what’s going on. It’s been awhile since I’ve felt so isolated, scared, on and on. Right now it’s as though nothing is enough to really help. I’m damned tired of this. I would like some help, too. I need it now. My daughter needs it now.”

Global Meaning

- Enduring beliefs
 - About the world
 - About the self
 - About the self in the world
- Valued goals
 - Purpose in life
- Understanding of past and present
- Expectations regarding the future
- That which is supposed to provide meaning in my life

Situational Meaning

- When situations happen, we draw on global meaning as we decide what to do
- We try to find meaning in situations that is consistent with our global meaning
- When that fails we may modify the situational meaning
- Ultimately we may shift our global meaning

The desire for offspring

- My life will only be fulfilled if I have biological offspring
- [“normal” is often implied]
- Infertility creates a situation that challenges global meaning
- Can be resolved by thinking of the situation differently – biology is not everything
- Or resolved by changing the global meaning – Love and family are more important than offspring

A child with CHARGE is a huge challenge to global meaning

- For most of us
- "I did not sign up for this."
- Even when managing the situation well (modifying situational meaning – "I have learned to appreciate the small things")
- This challenges the intended source of meaning in life – a healthy child

Victor Frankl



Viktor Frankl

"Man's search for meaning"

Sources of meaning in life

- Love, or experiencing someone deeply
- Doing a deed; accomplishing something
- Unavoidable suffering – suffering can have meaning



A CHARGEd life

- Love – we are here because we love our children with CHARGE and what they have taught us about love

A CHARGEd Life

- Doing a deed – we have learned so much and accomplished and achieved so much in our raising of our child.

A CHARGEd Life

- Unavoidable suffering – YES, it is really hard to parent a child with CHARGE. You have given up much, you have sacrificed much, you have cried many tears. But you would do it all over again.
- If you doubt your own strength, look at your child.

Resilience

- Attitude and shifts in global meaning
 - Choosing a social context
 - Choosing to bond
 - Choosing to learn and gain knowledge
 - Choosing one's experiences
- Resilient parents find a positive social support group, come to know their child in a way that creates a bond, learn as much as they can about their child's condition, and quickly acquire as much experience as they can in meeting the needs of their child.

Resources: resilient parents find the resources they need

- General and specific beliefs
- Problem-solving skills
- Health/Energy/Morale
- Material resources
- Social support
 - Network orientation
 - Seek and find

Parenting

It is hard enough to cope with raising a child who does not have obvious disabilities. Why in the world would you think you should know how to raise a child with tremendous needs?

Especially the behaviors!

"I've heard Tim talk about behavior multiple times and I still don't know how to cope with it."

Good-Enough Parenting

- Make your parenting errors with confidence
- Recognize there is no manual
- Trust your instincts, but be mindful of results
- Choose your battles wisely
- Be consistent when it matters
- Give as much freedom of choice as possible
- Know that children who feel good, do good
- Understand that misbehaviors may be creative solutions on the part of your child

Forgive Yourself

- For not being the parent your child deserved
- None of us gets the parents we deserved
- None of us is perfect



Pat yourself on the back

- You are resilient
- You are present
- You are making a tremendous difference in your child's life



Perfect courage is the courage to be imperfect.



Contact information

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Category: Behavior

**Saturday
Breakout Session #6:32: 1:00-2:00
Palomino 8 & 9**

**When Behavior Really Is Just
Behavior: What To Do?**

**Laurie S. Denno, Ph.D., BCBA-D
Behavior Analyst**

**Perkins School for the Blind
Simmons College
Antioch University New England**

Presenter Information:

Laurie S. Denno is a board certified behavior analyst and licensed mental health counselor. She works at the Perkins School for the Blind in the Deafblind Program as a behavior analyst. In addition, she is a supervisor in behavioral education at Simmons College in Boston and an instructor in Behavior Analysis at Antioch University New England. She has worked as a behavior analyst for 30 years and worked with children and young adults with CHARGE syndrome for over 20 years.

Presentation Abstract:

This presentation will outline the steps to take to assess challenging behavior in children with CHARGE syndrome. Parents will learn about the functions of behavior (reasons challenging behavior occurs). Treatment options and interventions will be discussed. This is a challenging and complicated enterprise. The bottom line may be to get professional help. Resources will be shared.



Category: Education,
Family Support

Saturday
Breakout Session #6:33: 1:00-2:00
Palomino 10

**National Recommendations for
Improving Intervener Services:
Discussion and Planning for
“Next Steps”**

**National Consortium on Deaf-Blindness
(NCDB)**
D. Jay Gense, Director
Peggy Malloy – Team Leader

Presenter Information:

Jay Gense and Peggy Malloy work with NCDB. Both have been involved with NCDB's efforts in responding to the U.S. Department of Education's Office of Special Education Program's (OSEP) request to 1) collect information and data that present a “snap-shot” of current intervener services in the United States; and, 2) use this information to develop recommendations for improving the availability and quality of intervener services.

We are very interested in gaining family perspective on the recommendations, and to solicit parent and family participation in implementation. During the session, we will discuss:

- What the recommendations are and how they were developed
- The role families played in crafting the recommendations, and the role families are playing and can continue to play to assist in moving forward with recommendation strategies
- a discussion of intervener learning modules now under development
- a facilitated Q&A regarding the need for quality intervener services.

Presentation Abstract:

In July 2012, the National Consortium on Deaf-Blindness (NCDB) released recommendations for improving intervener services for children who are deaf-blind (birth through age 21) in the United States. These recommendations, developed in response to a request from the U.S. Department of Education's Office of Special Education, were based on information gathered from an extensive data collection process and discussions with multiple stakeholders, including family members. This presentation will discuss the recommendations and plans for implementation.

3rd Professional Day & 11th International CHARGE Syndrome Conference
Fairmont Scottsdale Princess Hotel, Scottsdale, AZ July 25-28, 2013



Recommendations for Improving Intervener Services

GOAL 1: RECOGNITION

Increase recognition and appropriate use of intervener services for children and youth who are deaf-blind.

RECOMMENDATION 1

Develop a coordinated and expanded national approach to provide state and local early intervention and education agencies with information and tools needed to understand and use intervener services.

Implementation Strategies

- ❖ The National Consortium on Deaf-Blindness (NCDB), state deaf-blind projects, and other stakeholders (e.g., families, early interventionists, teachers, related service providers, early intervention and educational administrators, interveners, and university faculty), will join forces to implement a comprehensive national intervener initiative. The initiative, coordinated by NCDB, will:
 - Develop and disseminate a consistently applied *national definition* of intervener services, including clarification of the occupational role of the intervener.
 - Organize workgroups to implement the recommendations in goals 1 through 3 and identify additional needs and recommendations to improve intervener services. Workgroup topics will include, at a minimum:
 - intervener preparation and training;
 - continuing education needs of interveners;
 - coaching and supervision of interveners;
 - credentialing or certification of interveners;
 - interveners in community and home settings; and,

* Funded through Award #H326T060002 by the U.S. Department of Education, Office of Special Education Programs. The opinions and policies expressed by these recommendations do not necessarily reflect those of the U.S. Department of Education. and you should not assume endorsement by the Federal Government. Project Officer, Jo Ann McCann, Office of Special Education Programs.

- interveners for infants and toddlers.
 - Create a Web-based platform on which state deaf-blind projects, NCDB, families, and other organizations and individuals can interact and share knowledge. For example, this platform could be used to:
 - communicate ideas and concerns;
 - highlight intervener training and support models; and
 - access a shared video library related to intervener services (e.g., parent and professional insights, examples of interveners working with children).
 - Identify and implement strategies to increase collaborative efforts between agencies and organizations within individual states (e.g., state deaf-blind projects, PTIs, family organizations) to improve intervener services at the state level.
- ❖ Develop and make available a core set of publications that increase understanding of intervener services and promote their development and use. These materials should, at a minimum, include:
- concise fact sheets that a) promote an enhanced understanding of intervener services, and b) explain the occupational role of a well-trained intervener;
 - publications that highlight promising intervener-training and support programs and provide strategies that describe how they can be replicated; and
 - publications that describe effective practices for intervener services.
- ❖ Design and launch a national data collection program to collect, compile, and make available data about the use of intervener services, such as:
- characteristics of interveners (e.g., how many, where, education level), and
 - characteristics of children and youth who receive intervener services.

RECOMMENDATION 2

Coordinate and expand efforts to inform and influence national, state, and local policies and practices so that they reflect and support the provision of intervener services for a child or youth who is deaf-blind when needed.

Implementation Strategies

- ❖ Produce and disseminate guidelines that IFSP/IEP teams can use to make informed decisions about the need for initial or continued use of intervener services for an individual child or youth.
- ❖ Using the core products described in Recommendation 1:
 - promote best practices for intervener services via information dissemination and technical assistance activities; and,
 - systematically disseminate resources to lawmakers and other policymakers to inform and influence policies related to intervener services.
- ❖ Work with OSEP to encourage U.S. Department of Education cross-agency (e.g., OSEP, Rehabilitation Services Administration, National Institute on Disability and Rehabilitation Research) recognition of intervener services.
- ❖ Work with state and national special education organizations and centers (e.g., Regional Resource Centers, the National Association of State Directors of Special Education, Parent Training and Information Centers) to design and implement strategies that inform and influence policies and practices related to intervener services.
- ❖ Work with state special education advisory councils to raise individual states' awareness of intervener services.
- ❖ Contribute to the growth of knowledge related to intervener services in the following ways:
 - develop professional publications including technical reports or peer-reviewed journal articles that summarize available data about interveners and describe the history and current status of intervener services in the U.S.;
 - promote research on intervener services by:

- facilitating discussions among graduate students and researchers within the field of deaf-blindness;
- assisting researchers in identifying children and families who can participate in research studies;
- providing library support (e.g., literature searching) to researchers working in this area; and
- identifying possible funding sources for intervener services research.

GOAL 2: TRAINING & SUPPORT

Establish a strong national foundation for intervener training and workplace supports.

RECOMMENDATION 3

Develop national open-access intervener-training materials that align with the Council for Exceptional Children's *Specialization Knowledge and Skill Set for Paraeducators Who Are Interveners for Individuals with Deaf-blindness*.

Implementation Strategies

- ❖ Establish a workgroup of individuals with expertise in intervener training to collaborate with NCDB on the development of intervener-training materials.
- ❖ Invite professionals from the field of deaf-blindness to submit intervener or general deaf-blind education training materials for review by the workgroup and possible incorporation into the materials.
- ❖ Develop the training using new and existing materials.
- ❖ Create a web-based platform to house and provide free access to the materials.

RECOMMENDATION 4

Develop strategies to ensure that interveners have knowledgeable supervisors and access to experts in deaf-blindness who can provide consultation and coaching.

Implementation Strategies

- ❖ Use the intervener-training curriculum described in Recommendation 3 to train teachers and other team members about deaf-blindness and the role of the intervener.
- ❖ Identify successful models used by state deaf-blind projects, university programs, and school districts that provide on-the-job support to interveners.
- ❖ Replicate these models to support an increasing number of interveners.
- ❖ In partnership with a broad group of stakeholders, examine the causes of the shortage of local experts in deaf-blindness, including teachers of the deaf-blind, and identify strategies to alleviate the shortage.
- ❖ Design and implement strategies to provide distance consultation, coaching, and mentoring through the use of technology applications.

RECOMMENDATION 5

Expand opportunities for interveners to obtain a state or national certificate or credential.

Implementation Strategies

- ❖ Invite input from a broad group of stakeholders regarding:
 - preferred characteristics of credentialing processes and criteria;
 - current and future needs for an intervener credential; and,
 - short- and long-term goals of intervener credentialing.
- ❖ In partnership with stakeholders, including the NRCP and the National Intervener Task Force, determine the necessary criteria for an intervener credential.
- ❖ Identify credentialing bodies that could offer a national credential that meets those criteria.
- ❖ Determine the most feasible credentialing options and move forward with efforts to expand pathways to a national credential that are applicable to interveners with a variety of training backgrounds.

RECOMMENDATION 6

Establish a national intervener jobs clearinghouse to assist in intervener recruitment and job placement.

Implementation Strategies

- ❖ Convene a workgroup of interveners and other individuals who have knowledge of intervener hiring practices (e.g., educational administrators, state deaf-blind project personnel) to determine the design elements needed for an online jobs clearinghouse.
- ❖ Develop a secure online jobs clearinghouse reflecting those design elements.
- ❖ Publicize the availability of the clearinghouse through current intervener training programs, state deaf-blind projects, and other relevant agencies and organizations.
- ❖ Maintain the clearinghouse data on an ongoing basis.

RECOMMENDATION 7

Provide resources (e.g., technology applications, technical assistance) that assist interveners to establish organized online and face-to-face communities where they can improve their knowledge and skills by sharing ideas and experiences with each other.

Implementation Strategies

- ❖ Convene a workgroup of interveners, state deaf-blind project personnel, and university faculty to determine desired features of an online community of interveners.
- ❖ Develop and maintain a Web-based platform providing those features.
- ❖ Publicize the availability of the site and train interveners in its use.
- ❖ Explore opportunities for interveners to occasionally meet in person (e.g., state meetings, national or regional conferences).

GOAL 3: FAMILIES

Build the capacity of families to participate in decision about intervener services for their children and in efforts to improve these services.

RECOMMENDATION 8

Develop and disseminate information resources and tools to family members that increase their knowledge of intervener services and enhance their ability to communicate effectively with educators, administrators, and others about those services.

Implementation Strategies

- ❖ Review existing family-focused resources related to intervener services.
- ❖ Use existing resources (if available) or develop new products that families can use to:
 - promote communication about intervener services with early interventionists, educators, and administrators;
 - inform decisions related to intervener services for their child; and
 - inform and influence state and local policies to encourage and promote high-quality intervener services.
- ❖ Collaborate with family organizations to distribute information to families who have limited knowledge of interveners. This will include efforts to reach out to groups who are typically underrepresented (e.g., racial and ethnic minorities, families who live in rural areas, and families who are socioeconomically disadvantaged).

RECOMMENDATION 9

Develop and implement strategies that create opportunities for families to share ideas and experiences and work together to impact intervener services at local, state, and national levels.

Implementation Strategies

- ❖ Establish accessible Web-based and/or telephone groups where family members of children who are deaf-blind can share ideas and experiences about intervener services.
- ❖ Partner with key family organizations (e.g., NFADB, NDBII Parent Group) to implement strategies for recommendations that promote appropriate effective intervener services for children who are deaf-blind.
- ❖ Develop a curriculum module about intervener services to supplement current family leadership curricula that family members can use to educate themselves and to mentor others.

GOAL 4: SUSTAINABILITY

Sustain high-quality intervener services across the nation through the inclusion of intervener services in national special education policy.

Recommendation 10

Congress should ensure the long-term sustainability of intervener services for children and youth who are deaf-blind by including “intervener services” as a related service and as an early intervention service in the next reauthorization of the Individuals with Disabilities Education Act (IDEA).



Category: Parent Share
Medical

Saturday
Breakout Session #6:34: 1:00-2:00
Dorado

“Parent Share”
Medical

Betsy Bixler, M.Ed.
Deafblind Education
Perkins Training Center
Perkins School for the Blind
Watertown, MA 02472

Presenter Information:

Betsy is currently the Manager of Perkins Training Center, a professional development and continuing education program that provides lectures, workshops and courses to professionals and family members working with and on behalf of students with visual impairment and deafblindness. Included in the training plan conducted by the Perkins Training Center, are workshops and lectures that address critical topics that impact children with CHARGE syndrome.

Presentation Abstract:

This is the second of four facilitated sessions conducted for parents, each with an individual focus on the topics of: Behavior, Education, Adult Services and Medical.



Category: Education

Saturday
Breakout Session #6:35 1:00-2:00
Moor 2

LAMP
Words for Life

John and Cindy Halloran
The Center for AAC & Autism
Maumelle, AR72113 United States
john@aacandautism.com
cindy@aacandautism.com

Presenter Information:

John Halloran, a speech-language pathologist, is the Senior Clinical Associate for The Center for AAC and Autism and co-author of the Language Acquisition through Motor Planning approach. He has worked in the field of AAC since 1994. He has presented extensively in the US and abroad.

Cindy Halloran, an occupational therapist, is the Director of the Center for AAC and Autism and co-author of the LAMP approach. She has 25 years' experience exclusively in the field of pediatrics. She is NDT certified and has received training in the area of sensory integration.

Presentation Abstract:

There are no cognitive prerequisites for the implementation of LAMP (Language Acquisition through Motor Planning) as intervention can begin at the cause and effect level and systematically build upon the stages of natural language development. In order to maximize a student's language and communication development, one must presume the student has the potential to become a proficient communicator, provide a system that supports complex communication, but be able to teach the language in that system at a level commensurate with the learner's current abilities. Knowing the structure of an AAC (augmentative alternative communication) system that will support the desired outcome of complex communication allows the therapist to analyze the task and make individual modifications while supporting systematic growth and a continuum of learning.



Category: Education

Saturday
Breakout Session #7:36: 2:15-3:15
Palomino 1 & 2

“Insights on Using the iPad for Young Students with CHARGE Syndrome”

Gloria Rodriguez-Gil M.Ed.
Educational Specialists, CDBS

Cristi M. Saylor, M.A., M.S.
DHH Itinerant Teacher, SDCOE

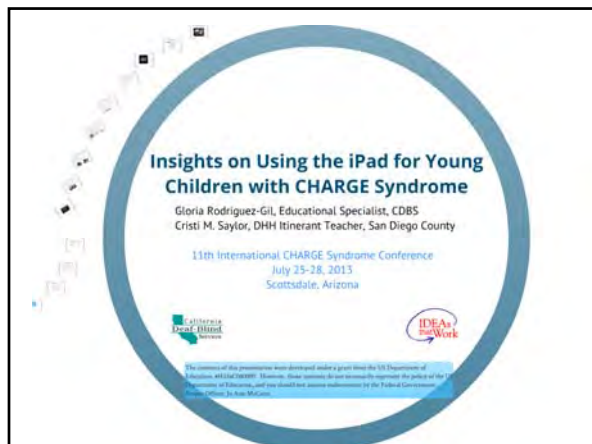
Presenter Information:

Gloria Rodriguez-Gil has 25 years in the field of visual impairments, multiple disabilities and deaf-blindness. She works for California Deaf-Blind Services, providing technical assistance, trainings and lectures. Find her articles and blogs at www.cadbs.org

Cristi M. Saylor, M.S., M.A., has worked in education for 25 years in various capacities. Her specialty lies in working with children who have multiple disabilities. Currently she works as a DHH itinerant teacher in the San Diego area.

Presentation Abstract:

This presentation will demonstrate solutions, usages, advantages and disadvantages of the iPad and propose a sequence for initial learning. Video clips of examples of young students using the iPad will be used to stimulate discussion. The presentation is appropriate for parents, educators, therapists, educational technologists and technical assistance providers for young students with CHARGE syndrome who wish to learn more about using iPads to better support their young children, student users, and their educational team.



Agenda

- Gain insights into the advantages, challenges and solutions of using the iPad with children.
- Learn a sequential approach to introducing the apps to young children.
- See a variety of creative uses of the iPad with a diverse population of children through the use of videos.
- Leave with a list of recommended apps and other resources.

Advantages



Advantages of the iPad

- Children's attention span, focus and reach increases due to attractiveness of screen and the cause and effect quality.
- It's fairly easy for child to activate and children with physical/medical problems can demonstrate their cognitive abilities.
- Children can use it in their different natural spaces (floor, lap of an adult, couch, desk, bed)

Advantages of the iPad (2)

- Children often respond even if they don't know the adult or if they are new to this technology.
- Apps offer different degrees of complexity which allows adults to discover and work at the child's level.
- Information can be presented in different format (e.g., default app content or content created on the spot).
- It can supplement other venues to assess the child.

Advantages of the iPad (3)

- It allows a "smooth" transition from concrete objects to pictures: 1) easy to show meaningful pictures, 2) allows manipulation of pictures
- The camera in the iPad is a great tool to create content and engage the child in the creation of content.

Challenges & Solutions



Challenges & Solutions

The screen is made of glass and its very glary and reflective

If you go outside it may be too shiny

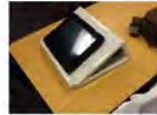
1. Use an antiglare matte screen cover
2. Position the iPad, the best you can, so there is no direct light hitting the screen



Challenges & Solutions (2)

The thinness and lightness of the iPad can adversely affect handling.

1. Hold onto the iPad for the child
2. Guide and support the child from the wrist when their touch needs to be more refined
3. Use an easel with non-slip material



Challenges & Solutions (3)

Visual busyness of the screen may make it difficult for the child to select desired icons

1. Be aware of the number of icons on the screen.
2. If possible have only a few icons (e.g., 1 or 2).
3. Be aware of contrast of pictures and text in relation to background.
4. Guide and support the child from the wrist to help locate icons if necessary.



Challenges & Solutions (4)

Limited attention span and need to move

1. Begin with an app that it is easy to use for the child
2. When appropriate, allow the child to make choices of apps to use.
3. Allow the child to take breaks but stay in the same place
4. Prevent the screen from shifting to other apps
 - iPad settings
 - General
 - "iPad Cover Lock/Unlock", turn it on
5. Use keyguards to prevent the child touching certain areas of the iPad (e.g., the home button)

<http://beyondadaptive.com>

Challenges & Solutions (5)

Joint attention between child and adult may be hindered because 1) difficult for child to divide attention or 2) child prefers to play alone

1. Respect child's space but encourage joint play by taking turns
2. Follow the child's lead
3. Place your face near the iPad

SEQUENCE

Sequential Approach to Introducing the Apps to Young Children

Using the iPad and a Sequence of Apps for Young Children with Multiple Disabilities.
ReSource, Fall 2012 (Vol. 17, No.2)
<http://www.cadlts.org/newsletter/>

The following apps will be featured in
 video clip showing sequence:

Tap-n-See Zoo (Little Bear Sees)
 Baby Finger (DJ International)
 Peekaboo Barn (Night & Day Studios, Inc.)
 Itsy Bitsy Spider HD (Duck Duck Moose)
 Match It Up 1 (My First App)
 Dot Collector (Ellie's Games, LLC)
 Verbal Victor (See Stage Associates)
 Go Away Big Green Monster (Night & Day Studios, Inc.)

Sequential Approach to Introducing the Apps to Young Children (8:08)



Video Clips of Children



Resources

- Using the iPad and a Sequence of Apps for Young Children with Multiple Disabilities
ReSource, Fall 2012 (Vol. 17, No.2)
<http://www.cadlts.org/newsletter/>
- Absolutely Engaging and Educational - Part 1: Using iPad Apps with Children with Visual Impairments and Additional Disabilities
https://secure2.conviso.net/pah/site/Ecommerce/1415866984?VIEW_PRODUCT=true&product_id=89416store_id=1641
- Absolutely Engaging and Educational - Part 2: Using the iPad Apps with Children with Visual Impairments and Additional Disabilities
https://secure2.conviso.net/pah/site/Ecommerce/VIEW_PRODUCT=true&product_id=88216store_id=1641

Resources

iExploration: Using the iPad for Vision Stimulation
https://perkins.adobeconnect.com/_a1042761236/p14svq5ajaz/?launcher=false&fcsContent=true&pbMode=normal





Category: Medical

Saturday
Breakout Session #7:37: 2:15-3:15
Palomino 4 & 5

Endocrine problems in CHARGE syndrome; what are they and how common?

Jeremy Kirk
Consultant Paediatric Endocrinologist
Diana Princess of Wales
Children's Hospital,
Birmingham,
United Kingdom

Presenter Information:

Consultant Paediatric Endocrinologist (Honorary Reader) Diana Princess of Wales Children's Hospital, Birmingham, UK. I have been Medical Adviser to the UK CHARGE Family Support Group for almost 20 years, and have over 50 children with CHARGE currently under my care. My special interests in CHARGE are regarding growth and hormonal problems.

My university provides CHD7 mutation screening for the UK, and I am currently in negotiation with Great Ormond Street Children's Hospital in London to set up specialist national CHARGE clinics. I am also organizing a national survey of children with CHARGE syndrome in the UK

Presentation Abstract:

That children with CHARGE Syndrome have hormonal problems is reflected within the acronym: genital abnormalities (the G in CHARGE) and also a contribution to short stature. Many children, especially boys, also have problems with puberty, due to deficiency of pituitary hormones.

Although it has been recognized for some time that hormonal problems are part of CHARGE syndrome, and also that there is crossover with other conditions, there is little documentation on what problems are found, and how common they are. We will present data from two very large endocrine units in the UK on over 100 patients which will show both frequency and range of hormonal problems in CHARGE Syndrome, and also their potential effects.

CHARGE Syndrome: Hormone defects; what are they and how common?

Dr. Jeremy Kirk

Consultant Paediatric
Endocrinologist

Diana, Princess of Wales
Children's Hospital,
Birmingham



CHARGE: the “R” and the “G”

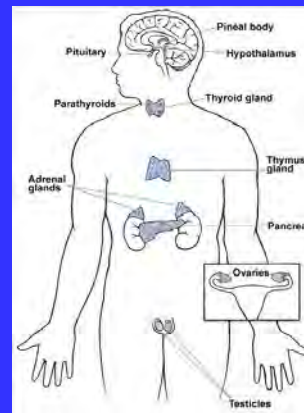
C
H
A
R
G
E

Retarded Growth

Genital/gonadal problems

What is a Hormone: *Wikipedia*

- “A **hormone** (from the Greek *ὁρμή* - “impetus”) is a chemical released by a cell or a gland in one part of the body that sends out messages that affect cells in other parts of the organism”.
- Endocrine hormones are secreted (released) directly into the bloodstream.



**Endocrine
system
glands**

What hormones are involved in CHARGE?

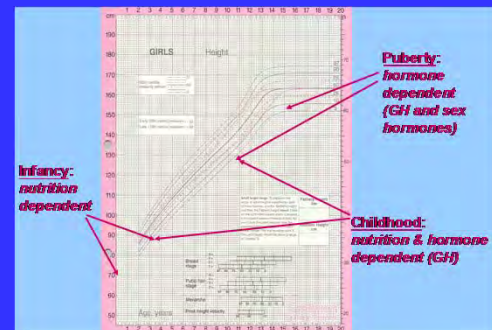
- **Growth:** Growth hormone, sex hormones, (thyroid hormone, stress hormone)
- **Genital development:** Sex hormones
- **Puberty:** Sex hormones, (adrenal)
- **Osteoporosis:** Sex hormones/Growth hormone

Introduction

- Growth and growth hormone therapy.
- Puberty and CHARGE.
- Osteoporosis and calcium status.
- The adult with CHARGE.
- CHARGE/Kallmann syndrome overlap.
- UK experience from 2 units.

Growth and growth hormone

Different growth components: all affected in CHARGE



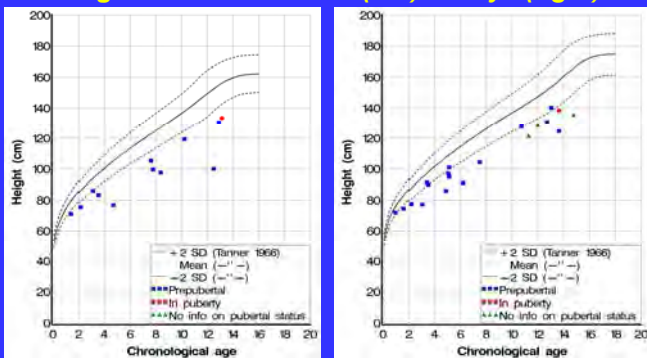
Diagnosis of growth hormone deficiency

- Growth:
 - height compared to parents
 - growth rate
- Bone age: estimate of “biological” age.
- Growth factors.
- GH stimulation test.

GH-deficiency and underactive pituitary (hypopituitarism)

- Incidence unknown in CHARGE syndrome.
- Probably more common than general population, especially in children with facial clefting.
- In GH treated patients:
 - USA 17 of 22 tested (77%)
 - Europe 19 of 26 tested (73%)

CHARGE syndrome (KIGS; Europe): Baseline data Height at GH start. Girls (left) & Boys (right)



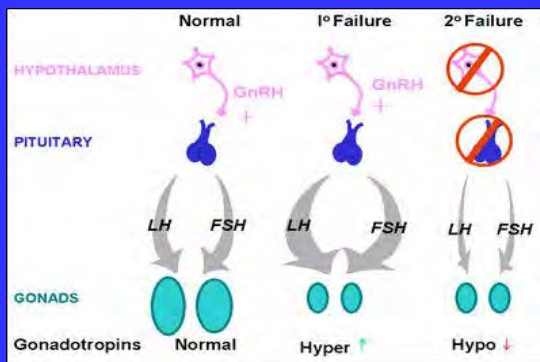
Comparison of US and European data



Puberty and CHARGE

Pointers to puberty problems

- Anosmia (absent sense of smell) in both sexes.
- Micropenis (pinch an inch?) }
• Undescended testicles } in males.
- NB: Remember that pubic hair alone "adrenarche" may be due to sex hormones arising from the adrenal glands.



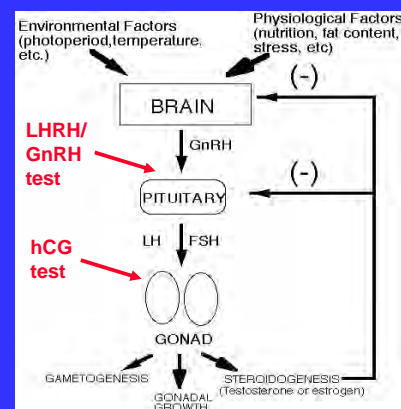
Forms of gonadal failure: central vs. peripheral

Diagnosis of puberty problems

- Delayed, absent or arrested? Definition of delayed puberty is absence by 13 years in a girl, 14 in a boy.
- Clinical staging: pubic, axillary (armpit) hair in both sexes, breasts in girls, genitalia and testicles in boys.
- X-Rays: Bone age, pelvic ultrasound (womb) & ovaries in girls.

Diagnosis of puberty problems

- Baseline "one-off" bloods (often not useful): LH, FSH, oestrogen (oestradiol) in girls, testosterone in boys.
- Stimulation tests:
 - LHRH tests "top end": hypothalamus and pituitary.
 - hCG (in boys) tests "bottom end": testicles.



Hormones involved in genital and puberty development and fertility

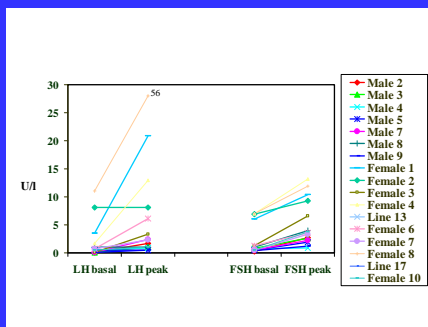
BCH experience: adolescents

- 20 patients (10 male) investigated at average age of 14.7 years (range 10.6-19.4).
- Of the boys 6 had micropenis, and 5 undescended testicles requiring surgery (orchidopexy).
- 6 patients (all female) have spontaneous signs of puberty (Breast Stage 2 or Testicular volume >4ml), and 2 have had spontaneous menstruation.
- 9 have had pelvic USS scan, with the uterus pubertal in 4.

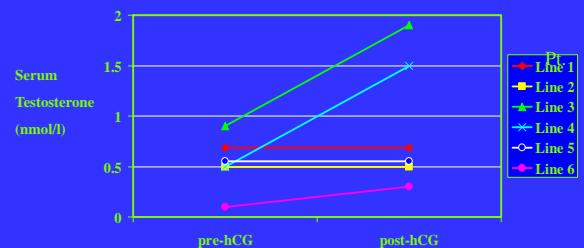
BCH experience: adolescents

- Four have been treated with GH: none are growth hormone deficient.
- 10 (4 males) have achieved final height, which is in the normal range ≥ -2 SDS (2nd centile) in 5 (range -7.5 to +1.8).
- 15 patients have had CHD7 testing, with 9 (60%) identified as having a mutation.

LHRH testing in CHARGE (N=14)



hCG testing in males with CHARGE (N=6)



Progress

- The seven oldest patients in Birmingham have required sex hormone replacement: oral ethinyl oestradiol in the girls, and testosterone (intramuscular depot in 3, oral in 1, gel in 1) in the boys.
- This has been reflected in other patients in the UK.

HRT: Concerns in CHARGE

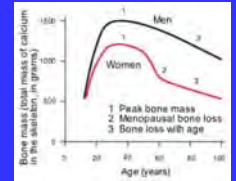
- Worsening behaviour.
- Inappropriate sexual behaviour.
- Menstrual bleeding (in girls).
- Persistent erections (priapism) in boys.

Must be balanced against long-term osteoporosis risks as much bone strength is laid down in late teens under influence of sex hormones.



Osteoporosis and calcium status

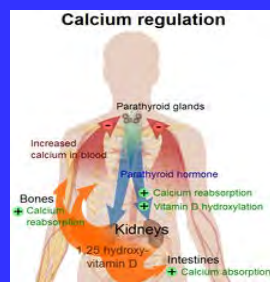
Osteoporosis



- 25% of bone mass is laid down during puberty, in the 2 yrs either side of peak growth rate (average 12 years in girls, 14 years in boys).
- Every 10% increase in bone mass is equivalent to a 50% reduction in fracture rate.
- Dietary factors are also important: a low calcium intake < 500 mg/day reduces bone mass gain.

Birmingham (UK) experience

- 22 CHARGE patients
 - 13 (59%) female
 - Median age 13 years: (range 1-23 years).



Levels of:
Calcium, phosphate normal in all.
Alkaline phosphatase (Alk Phos) raised in 2.

Birmingham (UK) experience

Parathyroid hormone (PTH) raised in 8 (including both with raised Alk Phos levels).

No patients with low PTH eg. Di George.

Vitamin D levels available in 17;

- Normal in 14 (82%)
- Insufficient in 2 (12%)
- Deficient in 1 (6%)

Adults and CHARGE

Adults with CHARGE (*LaRosa et al., 2009*)

- 8 subjects, 4 males and 4 females (aged 20-28 years), attending an adult endocrine clinic.
- 3 had received GH therapy; 2 were GH deficient.
- All had received sex steroid therapy; none had attempted fertility.
- Height and bone density compared with age-matched subjects affected by primary (Klinefelter Syndrome- Premature Ovarian Failure) and secondary hypogonadism (Hypogonadotrophic Hypogonadism).

Data on CHARGE syndrome patients & matched hypogonadal groups (LaRosa et al., 2009)

	CHARGE	Hypo-hypo	Klinefelter/ POF
Age	21.5	22	21.7
Height (cm)	158.6	165.4	172.5
Height SDS	-1.6	-1	-0.3
BMI	21.5	25.4	22.9
Spine T-score	-2.4	-1	-1.1
Hip T-score	-0.6	-0.2	-0.3

Adult data (N=11 (UCLH & BCH))

- All had low bone mineral density (BMD), 8/11 (73%) had osteopenia and 5/11 (46%) had osteoporosis.
- Vitamin D levels were measured in 6 subjects and was low in 1.

**CHARGE
and
Kallmann Syndrome
overlap**

**Kallmann
syndrome (KS)**

An association of:

- Central hypogonadism (hypogonadotrophic hypogonadism).
- Absent sense of smell (anosmia).
- Other clinical features eg. absent kidney, mirror movement (synkinesia) are also variably described.



Kallmann syndrome (KS)

- May occur sporadically, or be inherited in an autosomal dominant, recessive or X-linked recessive form.
- A number of different genes (~5) have now been identified, and account for ~30% of all cases.

Common features of CHARGE syndrome and KS (FGFR1 type)

- Anosmia.
- Hypogonadotrophic hypogonadism.
- Cleft lip and palate.
- Hearing impairment.
- External ear abnormalities.
- Iris coloboma.

KS and CHARGE syndrome

- 36 patients with KS and 20 patients with normosmic idiopathic hypogonadotropic hypogonadism (nIHH) in whom mutations in 4 Kallmann genes had been excluded were screened for mutations in CHD7.
- Three of 56 KS/nIHH patients had mutations in CHD7.

Jongmans et al. 2008

UK Experience

London: Great Ormond Street



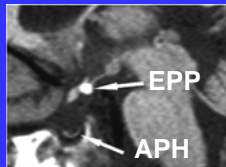
- Details on 28 patients (11 female); average age 14.0 years (Range 6-26).
- Eighteen diagnosed in neonatal period;
- Average age of referral to endocrinology was 3.6 years (Range 1 month – 10.9 years).
- Most common concern was short stature (mean height SDS at referral was – 2.4 (~0.4th centile).

London: Great Ormond Street



- Peak GH on testing (N=21) was 10.2 µg/l (Range 4.3-32).
- 11 treated with GH for 1-15 years (mean 9.4).
- 16 patients (11 males) had hypogonadotropic hypogonadism.
- Of 16 post-pubertal patients there was spontaneous puberty in 2 males and 3 females at a mean age of 11.3 years.

Pituitary abnormalities, hypopituitarism and CHARGE syndrome



- CHD7 sequenced in patients with hypopituitarism and structural abnormalities of the pituitary.
- 2 patients: 1 with ectopic posterior pituitary (EPP), anterior pituitary hypoplasia (APH), and GH, TSH, and probable LH/FSH deficiency, and EPP and APH with GH, TSH, LH/FSH, and ACTH deficiency in another patient, both of whom had features of CHARGE syndrome.
- Both had novel variations in CHD7.



Category: Family Support

Saturday
Breakout Session #7:38: 2:15-3:15
Palomino 6 & 7

The Power of Jacob

April Bieri, Heather Dziesinski, Raylen David, Tim Hartshorne, Ph.D.
Central Michigan University

Presenter Information:

April Bieri is a May 2012 graduate of Central Michigan University. She just completed her first year as a special education teacher in Clare, Michigan. In her spare time she likes to play with her puppy Millie, spend time with her husband Adam, visit Jacob, and visit her family.

Heather Dziesinski is a student at Central Michigan University majoring in special education, and currently student teaching. She is the most senior of Jacob's home intervenors.

Raylen Davis is on leave as a student at Central Michigan University where he majors in physical education and sport. He is currently pursuing a professional career in Mixed Martial Arts.

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. He has been researching and presenting about CHARGE syndrome since 1993, motivated by the birth of his son with CHARGE in 1989. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. He is first editor of the book *CHARGE Syndrome*.

Presentation Abstract:

Disability is often associated with a great deal of discouragement. How can a person with severe limitations possibly contribute to society? Jacob is a 24 year old young man who functions on the severe end of the CHARGE continuum. In this presentation, both by video and in-person, some of Jacob's caregivers will talk about his impact on their lives.

The Power of Jacob

April Bieri, Raylen Davis, Heather Dziesinski, Tim Hartshorne

Disability is often associated with a great deal of discouragement. How can a person with severe limitations possibly contribute to society? What power do they have to contribute? Aren't they just a drain on society's resources? Think about all the extra medical and educational supports they require, and consider all of what their parents and siblings have to sacrifice in order to provide for them. On the other hand, what does it really mean to contribute? There are people in the world with great gifts and opportunity who accomplish virtually nothing. It is not the gifts you have that make a difference in the world; it is what you do with those gifts. Jacob is 24 years old and has CHARGE syndrome, is deafblind, communicates through push/pull and pictures, and has many physical problems. Nevertheless, Jacob has changed many lives for the better, making a big impact on kids he went to school with and often their families, certainly his family, and his care givers. There are rich and powerful people in the world who have done nothing but ill with their gifts, and here is this kid with huge disabilities changing lives for the better. CHARGE syndrome does not define who our children are. We live in a society that does not get that disability is just different ability and that our kids have much to offer the world. Society needs to recognize that the investments we make in all children pay off. Jacob lives in his own home with continual support from caregivers. This presentation will feature a number of his support staff, some by video, and others on stage, discussing their experience of Jacob and his abilities, and how his use of those abilities has had the power to influence their lives.

Some things you should know about Jacob.

1. He is at the low end of the CHARGE spectrum in terms of his abilities.
2. His primary communication system is PECS or pictures.
3. Jacob is 24 and has lived in his own home for 3 years
4. Jacob has had 11-12 intervenors at a time who take shifts supporting his independence
 - a. College students

- b. Paid through Community Mental Health
- c. Focus is on safety, support, and increasing his independence

This presentation consists of the following:

1. A brief video about Jacob moving into his own home
2. Video of some of his caregivers talking about working with him
3. Three of his caregivers talking live about their experiences in working for Jacob





Category: Medical, Behavior

Saturday
Breakout Session #7:39: 2:15-3:15
Palomino 8 & 9

**Behavior, Psychiatry and
CHARGE Syndrome**

Laurie S. Denno, Ph.D., BCBA-D
Behavior Analyst
Perkins School for the Blind

John Julian, M.D.
Child and Adolescent Psychiatrist
Massachusetts General Hospital

Presenter Information:

Laurie S. Denno, Ph.D., is a behavior analyst at the Perkins School for the Blind, Deafblind Program, and also in private practice serving adults with developmental disabilities in residential and day programs. She has worked with children and young adults with CHARGE syndrome and behavior challenges for 20 years.

John Julian, M.D., specializes in child and adolescent psychiatry and also specializes in developmental disabilities. He has consulted to the Perkins School for the Blind for 10 years and worked with many children who have CHARGE syndrome. He is affiliated with Massachusetts General Hospital.

Presentation Abstract:

This presentation will outline Laurie's dissertation research that taught parents who were considering a psychiatric consultation how to discuss their child's challenging behavior with a psychiatrist in a specific and organized manner. Dr. Julian will discuss the process and function of a psychiatric consultation, what parents can expect during an appointment, how a diagnosis is made and how treatment is prescribed. We plan on leaving lots of time for questions and answers. This is an educational presentation.

Behavior, Psychiatry and CHARGE Syndrome

Laurie S. Denno, Ph.D., Behavior Analyst
Perkins School for the Blind

John Julian, M.D., Psychiatrist
McLean's Hospital
Perkins School for the Blind

What Are the Results?

- Did we change the behavior?
- Did we change the behavior enough?
- Do troublesome behaviors remain?
- Do these behaviors seem not to respond sufficiently to behavior treatment?
- What kind of behaviors remain?
 - Overly sad or withdrawn (crying, not participating)
 - Overly active (can't sit still, goes from one thing to the next, never finishes)
 - Erratic behavior (crabby, irritable, unpredictable)
 - Up and down mood (laughing and then crying)
 - Engages in repetitive behaviors with no purpose and when you interrupt them, the child may become aggressive or self-injurious

Behavior

- First we collect data on behaviors of concern, behaviors that interfere with learning
- We define the behavior very specifically: hitting, throwing, yelling, lining things up, checking, repeatedly closing doors or shutting off lights, irritability, increased or over activity, decreased or under activity, sudden changes in behavior, unusual behaviors, behaviors not observed before
- Frequency, duration, intensity
- Use a rating scale for the magnitude of interference—also specifically defined

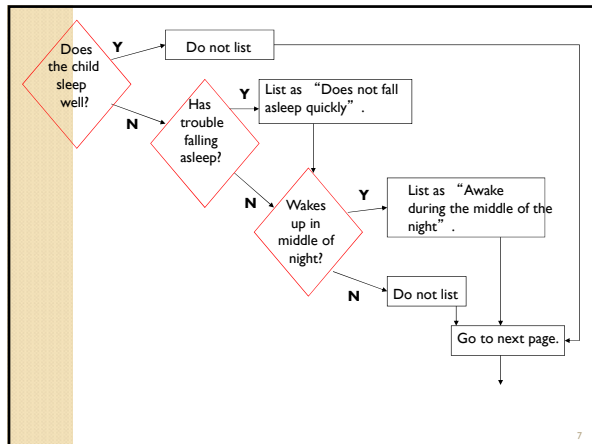
When to Call the Psychiatrist

- Implement good behavior treatment across settings with consistency
- You have several weeks or months of data on the frequency, duration or magnitude of the behaviors
- Troublesome behaviors remain
- It might be time to get a referral from your family doctor

- Functional behavior assessment looking at antecedents and consequences—environmental variables that cause or maintain the behavior
- What does the student get or avoid by engaging in the behavior?
- Design a behavior support plan that will be implemented across settings
- Implement the plan and continue with data collection
- Adjust the behavior support plan to get more benefit
- Apply consistently

Preparing for Your Appointment

- School and home implement a behavior plan but usually parents go to the appointment
- Parents are often nervous and do not know what to expect or what information to bring
- Best to make a list of troublesome behaviors
- Take your data, both home and school
- Make a list of questions to ask
- I have designed a self-directed teaching program for parents preparing for such an appointment that results in a list of remaining troublesome behaviors and a list of questions
- laurie.denno@perkins.org



Psychiatry

- Dr. Julian will provide a brief overview of what to expect during a psychiatric consultation.
- He will be happy to answer parent questions.



Category: Adult

Saturday
Breakout Session #7:40, 2:15-3:15
Palomino 10

They're Not Children
Anymore: communicating
effectively with adult
providers

James Schwark RN, MSN, MDiv, CRRN
Credentials & Organization
Coordinator for Simulation and Skills Labs
Azusa Pacific University School of Nursing
San Diego, CA

Presenter Information:

James Schwark learned many nursing skills providing care for his daughter through the multiple surgeries and other medical issues CHARGE families learn to know so well. He eventually formalized his training by earning his nursing license and ultimately has become a professor of nursing at Azusa Pacific College School of Nursing. His journey has taken him from the role of caregiver through the role of bedside nurse to the role of communicating to his students what he has learned along the way. Along the way he has seen CHARGE Syndrome from the perspectives of patient, caregiver and provider and he incorporates all these perspectives as he seeks to communicate better with adult practitioners his daughter has transitioned to.

Presentation Abstract:

How can we CHARGE experts help busy adult practitioners care for our young adults with CHARGE? Much of the information on CHARGE is focused at pediatric professionals since early intervention is so crucial. However, our children with CHARGE are moving beyond pediatric practitioners to the world of adult practitioners, many of whom know little of CHARGE. This presentation calls upon experiences as CHARGE father, floor nurse and nursing instructor to present strategies for better communication with adult practitioners.



They're Not Children Anymore: communicating effectively with adult providers

James Schwark RN, MSN, MDiv, CRRN
Simulation and Skills Coordinator
Azusa Pacific University
School of Nursing
San Diego



objectives

- ✦ Discuss the different perspective adult practitioners possess in contrast to pediatric practitioners.
- ✦ Identify the knowledge and expertise contained in families who live with CHARGE.
- ✦ Encourage a willingness to ask for clarification and explanation.
- ✦ Propose methods of communication which promote hearing.
- ✦ Discuss the need for persistence.
- ✦ Encourage a willingness to seek providers who are willing to learn.

The Charge of the Light Brigade

Half a league half a league,
Half a league onward,
All in the valley of Death
Rode the six hundred:
Theirs not to make reply,
Theirs not to reason why,
Theirs but to do & die,
Into the valley of Death
Rode the six hundred.

Cannon to right of them,
Cannon to left of them,
Cannon in front of them
Volley'd & thunder'd;
Storm'd at with shot and shell,
Boldly they rode and well,
Into the jaws of Death,
Into the mouth of Hell
Rode the six hundred.

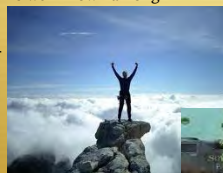
Lord Alfred Tennyson (excerpted)

PAR AVION



Great job! (so far)

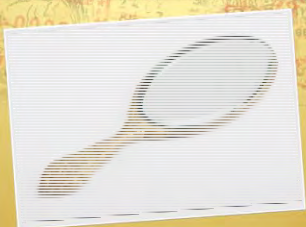
CHARGE is well known among
pediatric
providers
with their
focus . . .



. . . but not among adult
providers who have a different
focus

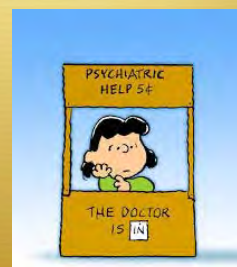



Call in the expert



Call in the expert

- ✦ You are the experts






Call in the expert
Hit the ground running

Hit the ground running


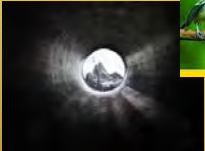
- ✦ Keep good records
 - comprehensive file
 - focused file
- ✦ Know the history
 - diagnoses
 - treatments
 - surgeries
 - medications

Call in the expert
Hit the ground running
Ask questions

Ask Questions

- ✦ Responsibility to educate
- ✦ Responsibility to learn

✦ Potential for tunnel vision




Call in the expert
Hit the ground running
Ask questions
Report & Resources

Report & Resources

- ✦ SBAR communication
- ✦ Suggest websites
- ✦ Provide resources
- ✦ Identify research
- ✦ Participate in studies



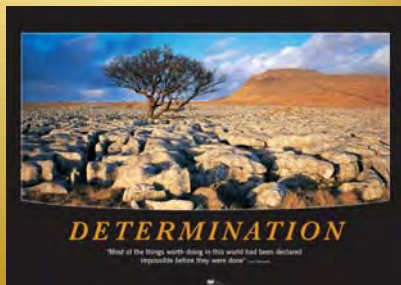




Call in the expert
Hit the ground running
Ask questions
Report & Resources
Grind away

Grind Away

- ★ Commit yourself to spending the time and expending the effort to get what you need. Expect that what you are asking for will take more than one request and more than just a little of your time.




Call in the expert
Hit the ground running
Ask questions
Report & Resources
Grind away
Explore

Explore

Your doctor,
case worker,
therapist . . .



. . . is not the
only one in
the world.

Call in the expert
Hit the ground running
Ask questions
Report & Resources
Grind away
Explore



Category: Parent Share
Education

Saturday
Breakout Session #7:41: 2:15-3:15
Dorado

“Parent Share”
Education

Betsy Bixler, M.Ed.
Deafblind Education
Perkins Training Center
Perkins School for the Blind
Watertown, MA 02472

Presenter Information:

Betsy is currently the Manager of Perkins Training Center, a professional development and continuing education program that provides lectures, workshops and courses to professionals and family members working with and on behalf of students with visual impairment and deafblindness. Included in the training plan conducted by the Perkins Training Center, are workshops and lectures that address critical topics that impact children with CHARGE syndrome.

Presentation Abstract:

This is the third of four facilitated sessions conducted for parents, each with an individual focus on the topics of: Behavior, Education, Adult Services and Medical.



Category: Medical

Saturday
Breakout Session #8:42: 3:30-4:30
Palomino 6 & 7

"Physical Therapy for a Child
 with CHARGE syndrome"

Danielle Bushey , PT, MS, NCS
Mary Poblete, PT, DPT
Perkins School for the Blind

Presenter Information:

Danielle Bushey has almost 10 years of experiences as a physical therapist, specializing in working with children and adults with neurological involvement. She has been a physical therapist at Massachusetts General Hospital and Spaulding Rehabilitation Hospital in Boston.

Her experience includes in-patient and out-patient settings, as well as public school. She has a focused interest in working with patients with vestibular involvement. She has been certified as a Neurological Clinical Specialist by the American Physical Therapy Association. She has been working with students with CHARGE syndrome for 3 years at the Perkins School for the Blind in the Deafblind program.

Mary Poblete has 6.5 years experience as a physical therapist, primarily working with the pediatric population. She was a physical therapist at Children's Hospital of Orange County in Orange, California, where she worked with children 0-21 years of age with various orthopedic, neurologic and oncology diagnoses. She has been working with students with CHARGE syndrome for 3.5 years at Perkins School for the Blind in the Deafblind Program.

Presentation Abstract:

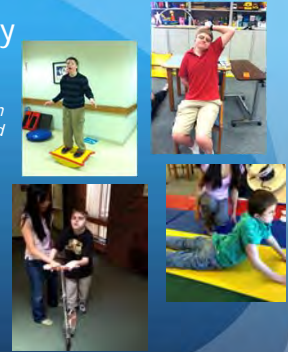
Physical therapy for children with CHARGE Syndrome requires extensive knowledge of the balance systems and the areas that have been compromised. An understanding of the principles of motor learning, as well as accommodations for behavioral, communication and learning challenges, are essential in a successful treatment session. Through photo and video of individuals with CHARGE Syndrome, we will be able to present the importance of physical therapy through functional activities to improve balance.

Physical Therapy and CHARGE syndrome

Danielle M Bushey, PT, MS, NCS
Mary Poblete, PT, DPT

Physical Therapy

- Physical therapy is "a dynamic profession with an established theoretical and scientific base and widespread clinical applications and the restoration, maintenance, and promotion of optimal physical function."



Role of a physical therapist

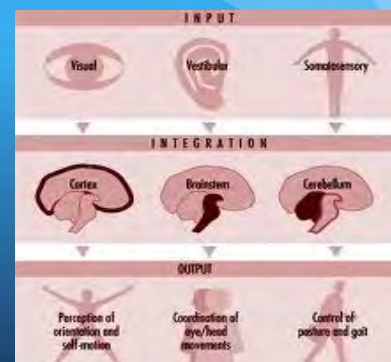
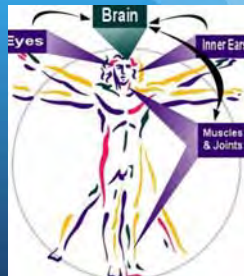
- Diagnose and manage movement dysfunction and enhance physical and functional abilities
- Restore, maintain and promote, not only optimal physical function, but optimal wellness and fitness and optimal quality of life as it relates to movement and health
- Prevent the onset, symptoms, and progression of impairments, functional limitations, and disabilities that may result from diseases, disorders, conditions, or injuries

What are the physical challenges of individuals with CHARGE?

- Cardiac
- Respiratory
- Tone
- Range of motion
- Posture
- Balance
- Coordination
- Vision
- Hearing
- Cranial Nerve
- Other comorbidities:
 - Surgical intervention
 - Developmental delay
 - Medication side effects
 - Nutrition

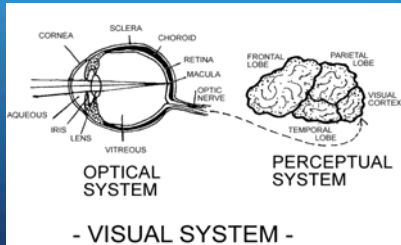
The complex BALANCE system

- Balance is maintained through a complex interaction of the Central Nervous System (CNS) and the three primary sensory systems:
- VISION
- VESTIBULAR
- SOMATOSENSORY



Visual System

- A strong inhibitor of the other two systems (vestibular and somatosensory)

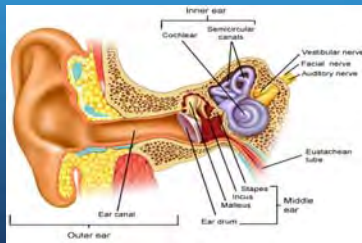


Somatosensory System

- The perception of sensory stimuli from the skin and internal organs of the body
- It is the fastest of the three sensory systems
 - light touch
 - proprioception
 - deep pressure
 - temperature
 - kinesthesia
 - vibration

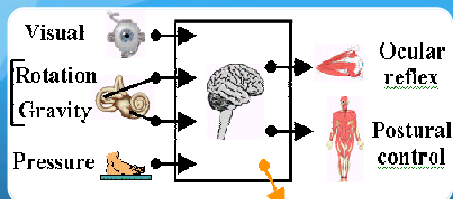
Vestibular System

- The conflict resolver between the other two systems (vision and somatosensory)



Why do individuals with CHARGE have such a difficult time with balance?

- Vision
 - Colobomas
 - Retinal Detachments
- Somatosensory
 - Low tone (joint laxity and decreased proprioception)
 - Sensory processing issues (defensiveness, regulation)
- Vestibular
 - Semi-circular canals
 - Cranial Nerve VIII impairment



If only it were so simple:

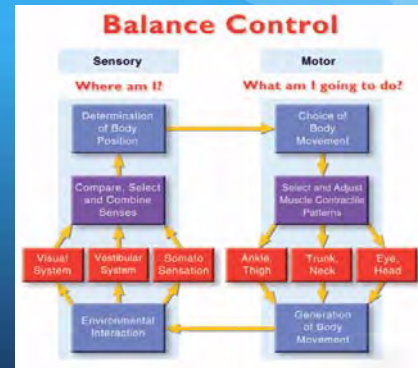
Neural connections
System coordination

Motor Control

- Area of study dealing with understanding of the neural, physical, and behavioral aspects of movement.

Motor Control

- Stimulus identification =>
- Response Selection (stimulus processing) =>
- Response Programming (motor output)



Motor Learning

- The improvement of a given functional task resulting from practice or experience. In order for the motor learning to be meaningful, the performance of the new task must be reproducible over time, performed in multiple environments and generalized to similar activities

Principles of Motor Learning

- Amount of practice
- Learner needs to be actively involved
- Task conditions (speed, timing, and environmental conditions)
- Adaptability
- Reinforcement is required
 - Knowledge of results
 - Feedback can be decreased over time

CHARGE and Learning

How do you make a PT session successful with students with CHARGE syndrome?



UNDERSTANDING and KNOWING your student

- Mode of communication
- Behaviors and behavior plan
- Need for structure and routine
- Obsessive Compulsive Disorders
- Limitations



Methods of Developing a Relationship

- Team approach - Communicate with teacher, family members, speech therapist, occupational therapist, Orientation and Mobility specialist, Behavioralist
- Communicate with your student
 - Sign language (visual and tactile)
 - Photos
 - Verbal



Methods of Developing a Relationship

- Avoid power struggles
- Give lots of positive feedback
- Clear expectations
- Sandwiching non preferred activities in between preferred activities
- Choice making
- Mood induction



How should we approach our students?

- Be flexible
- Be patient
- Limit expectations
- Accept slow progress

How to justify physical therapy

- Need to have measurable and functional goals.
 - Need to show progress
- They need to relate to a "disability"
 - Unable to participate in a school sports team
 - Unable to safely play on playground equipment
 - Unable to use stairs for fire safety
 - Unable to walk outside without falling
 - Unable to negotiate curbs or ramps in the community
 - Strength and endurance limit the ability to participate in vocational work

Expanded Core Curriculum

- How does physical therapy relate to access to education?
- It's not just about being able to walk from one class to another or negotiating stairs!

Expanded Core Curriculum

- The National Advisory Council of the Nation Agenda states that blind and visually impaired students have two sets of essential educational experiences: (1) regular curriculum offered to all students-the core curriculum - and (2) learning experiences required because of vision loss - the expanded core curriculum.

ECC Components

- Compensatory, Functional Skills, Lang/Communication
- Career Education
- Social Interaction/Group
- Independent Living Skills
- Leisure and Recreation/APE
- Orientation and Mobility
- Assistive Technology
- Sensory Efficiency
- Self-Determination

How does the ECC relate to physical therapy?

- Compensatory, Functional Skills, Language/Communication
- Career Education
- Social Interaction/Group
- Orientation and Mobility
- Sensory Efficiency
- Self-Determination

How can physical therapists advocate for their students with CHARGE syndrome

- Understand the importance of functional activities
- Understand the importance of improving balance and coordination for safety in all environments
- Understanding the importance of improving and maintaining flexibility, strength and endurance

Recommendations:

- Exercises: strengthening and stretching
- Follow-up with an orthopedist and/or physiatrist for monitoring of scoliosis, hip integrity, kyphosis, and need for foot bracing.
- Proper seating: to decrease postural fatigue (armrests, feet on floor), prevent postural mal-alignments
- Changes in position for sensory input and to decrease postural fatigue

Balance training in a setting in which the individual can be an active learner. Give the individual with CHARGE syndrome the opportunities to explore, fall, progress and LEARN.



Category: Behavior

Saturday
Breakout Session #8:43: 3:30-4:30
Palomino 8 & 9

MAKING SENSE OF BEHAVIOR:
The relationship between
sensory input and motor output

Kate Beals, OTR/L
South Carolina Interagency Deaf-Blind Project,
South Carolina School for the Deaf and the
Blind
Spartanburg, SC, USA

Presenter Information:

Kate Beals is an Occupational Therapist with 16 years of experience working with children. For the past five years she has worked with the South Carolina Interagency Deaf-Blind Project, providing training and support for the families and educational teams of children who have combined vision and hearing challenges, often with multiple and complex disabilities. Kate returned to college to become an occupational therapist when her now 23-year-old son, who has autism, was three years old. Kate believes that if she had known anything about sensory integration and behavior during her son's *first* three years of life, a great deal of suffering – on *both* their parts – might have been prevented. The opportunity to share her personal and professional experience with other parents confers meaning to those difficult years, and to the ones that followed.

Presentation Abstract:

Individuals with CHARGE Syndrome are known to have differences in the way they register, process, and integrate information from their sensory systems. When sensory input is absent or distorted, then motor output (behavior) may appear inappropriate to others whose sensory systems are intact. By understanding sensory processing differences in CHARGE Syndrome, parents and professionals will also achieve better understanding of the behaviors – problematic at times – that may occur as a result of these differences.

Making Sense of Behavior: The relationship between sensory input and motor output

11th International CHARGE Syndrome Conference
Scottsdale, AZ, USA July 26-28, 2013



Kate Beals, OTR/L
South Carolina Interagency Deaf-Blind Project

Session Objectives

I hope that this session will help to increase:

1. Awareness of the structures and functions of the seven main sensory systems in an intact state.
2. Awareness and understanding of differences in the structures and functions of the seven main sensory systems that may occur in an individual with CHARGE Syndrome.
3. Understanding of the behaviors that may occur as a result of sensory processing differences.
4. Awareness of resources regarding assessment and intervention for sensory registration, processing and integration issues for their children/students who have CHARGE Syndrome.



The Brain



• Sensory in

- Messages (input) from all 7 sensory systems travel to the brain on "inbound" tracts of the nervous system.
- It is a **one-way** street.
- **Sensory** information only goes **IN**.

• Motor out

- Messages (output) travel to the muscles on motor pathways, or "outbound" tracts of the nervous system.
- It is a **one-way** street.
- **Motor** instructions only go **OUT**.

Seven Sensory Systems

1. **Visual** – what we see
2. **Auditory** – what we hear
3. **Gustatory** – what we taste
4. **Olfactory** – what we smell
5. **Light touch** – what we feel on our skin (protective touch)
6. **Proprioception** – what we feel in our joints and muscles (body position)
7. **Vestibular** – movement and position of the head in space



Have you ever said this?



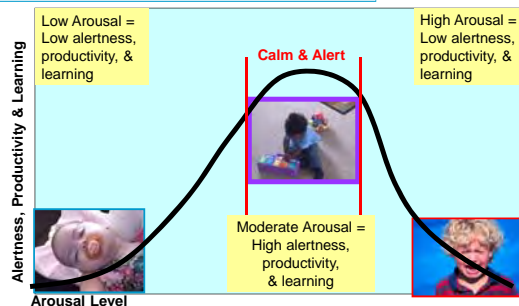
Hey, quiet down
back there
so I can see where
I'm going!

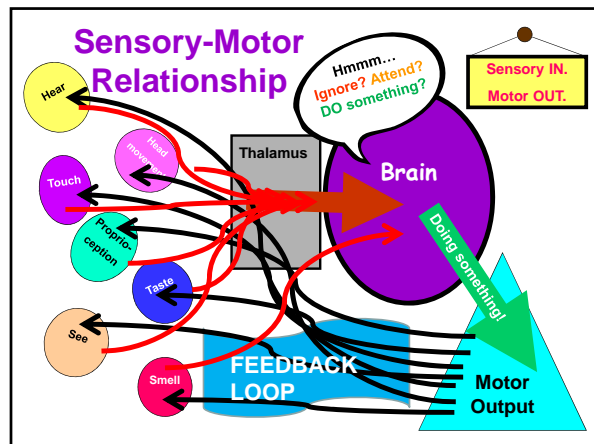
Sensory Integration

Brain takes in information from all 7 systems and decides what is **relevant**, **irrelevant**, and **whether an active motor response is called for**. We all have times when we need to "turn off" one sensory channel so we can attend better to a different one.

Arousal and Alertness

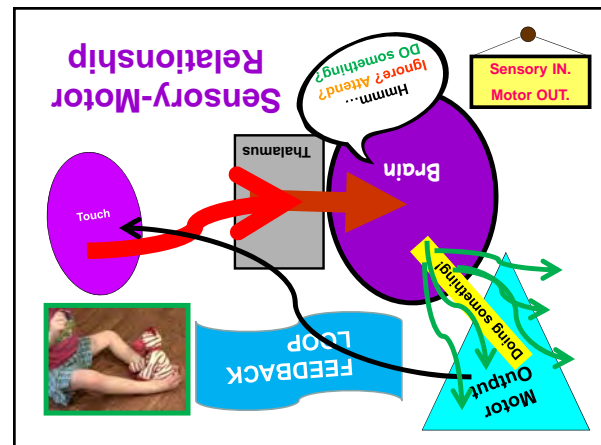
Sensory input from all seven systems contributes to our arousal level and state of alertness.





Assumptions

- Studies of the process of human development reveal that a certain amount of stimulation (meaning **sensory** stimulation) is necessary for the brain to grow and develop.
- "If 2 or more (**sensory**) systems are functioning below normally expected levels...then the baby usually experiences delays in adaptation to the environment." (Human Development textbook)
- Children with CHARGE Syndrome are likely to have impairment of not only 2 out of 7, but 6 out of 7, or even 7 out of 7 sensory systems.



It might look inappropriate for the situation as it is perceived by Others

So, what's the difference between how sensory systems work in general, and how they work in CHARGE Syndrome?

Let's look at the **Cranial Nerves**: Vision, Hearing, Tactile, Taste, Smell, Proprioception, Vestibular, and Balance systems.

Cranial Nerve Involvement

Cranial nerve anomalies are very frequent in CHARGE.

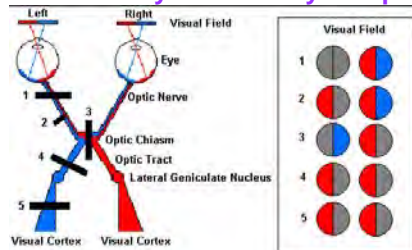
- 12 cranial nerves
- Begin in the brain
- Extend to structures in the head and neck
- Both motor control and sensation
- Nerves involved in the senses of smell, taste, hearing, and vision (sensory)
- Movements of the eyes, face, tongue, palate and swallowing (motor)
- Some cranial nerves are involved in control of heart rate and movements of the gastrointestinal tract.
- At least 1 cranial nerve is involved in 75% of CHARGE cases
- 2 or more are involved in 58% of cases



Bruce R. Korf, MD, PhD; CHARGE Syndrome Manual

Visual System - 1

The Visual System is very complex!



Receptors called **rods** respond to movement.
Receptors called **cones** respond to color and detail.
Pathway: Optic nerve.

Vision in CHARGE

Differences

- Coloboma: 80 – 90%
 - iris, retina, optic nerve
- Field loss – usually upper
- Possible microphthalmia
- Acuity deficits – 90%
- Light sensitivity
- Strabismus or amblyopia
- Sometimes CVI
- Facial Palsy – 40%
 - Lack of blinking causes dry cornea, leading to corneal scarring

Functional Implications

- May need a “quiet” visual environment
- Present materials in best (usually lower) visual field for access
- Seeing is **HARD WORK**:
 - might need supported body position or to “turn off” other senses
- Contributes to problems with **Balance**

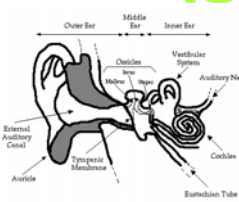
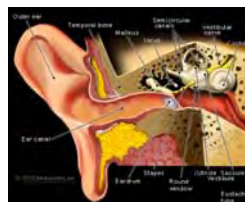
Roberta Pagon, MD, CHARGE Syndrome Manual

“Look at the camera.”



Photo courtesy of California Deaf-Blind Services

Auditory System - 2



Sound waves enter the ear, the eardrum vibrates which moves the three tiny bones in the middle ear. These connect via the oval window to the inner ear, where the hair cells in the cochlea transform the waves into electrical impulses the brain can perceive and understand.

Pathway: Vestibulocochlear Nerve (VIII Cranial, also “Auditory”)

Hearing in CHARGE

Differences

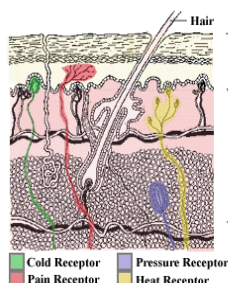
- Structural differences of inner ear
- Cranial nerve VIII, “Auditory Nerve” involvement
- Significant hearing impairment is common

***NOTE**
Cranial nerve VIII is also called the “Vestibulocochlear nerve”.

Functional Implications

- May need to explore alternate forms of receptive and expressive communication
- May need to explore supports for auditory function such as cochlear implant, hearing aids, FM system, etc.
- May not be able to use hearing for echolocation during travel

Tactile System - 3



There are many different types of sensory receptors in the skin, specialized for pain, heat, cold, light touch, firm touch (pressure), static touch and moving touch.

Pathway:

- Pain, temperature, nondiscriminative (crude) touch, pressure, and some proprioceptive sensation travel on the Anterolateral (ALS) system.
- Discriminative (fine) touch, vibratory sense, position sense travel on the Dorsal Column Medial Lemniscal (DCML) system.

Two functions of touch:

- Protection and discrimination.

Tactile in CHARGE

Differences

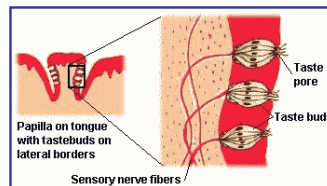
- Possible increased or decreased tactile awareness
- Tactile defensiveness due to early frequent hospitalizations, surgeries, and/or neurological processing differences



Functional Implications

- May use feet to explore
- May dislike unexpected touch, other kids getting too close, being touched around face or trach
- May benefit from Wilbarger therapeutic brushing protocol
- Don't force tactile exploration – make it fun!!!
- Hand-UNDER-hand technique is recommended

Gustatory System - 4



We have almost 10,000 taste buds inside our mouths! A single taste bud contains 50–100 taste cells representing all 5 taste sensations: salty, sour, sweet, bitter, and umami (savoriness). **Pathway:** Facial, Glossopharyngeal and Vagus Nerves (Cranial Nerves VII, IX and X).



Taste in CHARGE

Differences

Three of the four cranial nerves most likely to be involved in CHARGE Syndrome affect taste:

VII. Facial:

- controls most facial expressions
- secretion of tears & saliva
- **taste**

IX. Glossopharyngeal:

- **taste**
- senses carotid blood pressure

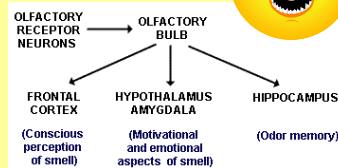
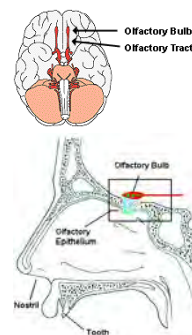
X. Vagus:

- senses aortic blood pressure
- slows heart rate
- stimulates digestive organs
- **taste**

Functional Implications

- **Good taste** is not a motivator
- **Bad taste** is not a deterrent
- Limited exposure to taste due to g-tube feedings
- Oral defensiveness to texture is likely due to early g-tube feedings as well

Olfactory System - 5



Pathway: Unlike the other senses, olfactory information goes straight to the frontal cortex of the brain without going through the thalamus first. It travels on the Olfactory Nerve (Cranial Nerve I).

Smell in CHARGE

Differences

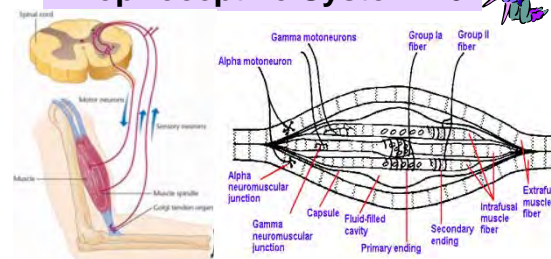
- Anosmia (inability to smell) is a frequent feature of CHARGE Syndrome
- Structural differences – many are missing olfactory bulbs and stems
- Nasal blockages are common (bilateral choanal atresia)
- Cranial Nerve I (Olfactory) involved in approx. 40%
- Study showed 100% correspondence between anosmia and problems with onset of puberty

Functional Implications

- What we think of as a "bad" smell may not be aversive
- Safety – can't smell smoke from a fire, gas leak, spoiled food
- Social – unaware of body odors
- Smell is powerful - linked to memory, learning, and bonding – reduced access

Jorieke Bergman, MD, and
Conny von Ravenswaaij-Arts, MD, PhD

Proprioceptive System - 6



Proprioception is awareness of body position. Receptors are in the muscles, joints, and tendons. Receptors react to stretch and compression. It is an unconscious feedback system between the body and the brain. **Pathway:** Spinocerebellar Tract. **Function:** Body position, graded movement (how much force?), awareness of gravity.

Proprioception in CHARGE

Deep pressure; discriminative touch; position of the BODY in space; awareness of gravity; body awareness

Differences	Functional Implications
<ul style="list-style-type: none"> Little research, but behavior and motor patterns suggest diminished proprioceptive awareness. 	<ul style="list-style-type: none"> Movement patterns resemble those of a person with reduced proprioception Late to walk Needs extra time to learn new motor routines Contributes to problems with Balance

VIDEO
Dr. Jessel and Mary Beth

<http://media.hhmi.org/hl/08Lect3.html>


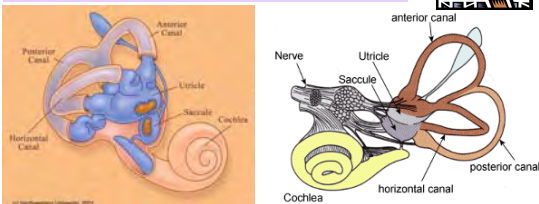


Photo and quote below are from
The forgotten sense: Proprioception,
By David Brown in
Deafblind International Review,
July – December, 2006

"In order to use her residual vision to look at fine details in a book Amy needs to be horizontal with her entire body and head fully supported: having one ankle up on the other knee sends her brain a strong message, through the proprioceptive sense, that her lower body is fixed and stable and not moving."
- David Brown

Vestibular System - 7



The Vestibular System responds to changes in gravity and acceleration of the head (up/down, forward/back, side to side). Fluid inside the canals sloshes against hair cells, causing them to bend. The degree and direction of the bend translates to position of the head in space. Semicircular canals sense rotation. Utricle and saccule sense up and down.

Pathway: Vestibulocochlear Nerve (Cranial nerve VIII)

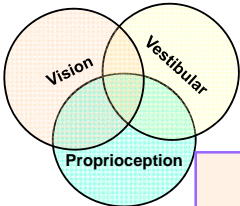

Vestibular in CHARGE

Movement; position of the head in space

Differences	Functional Implications
<ul style="list-style-type: none"> ABSENCE OR UNDERDEVELOPMENT OF SEMI-CIRCULAR CANALS Cranial nerve VIII* ("Vestibulocochlear") may be absent or displaced 	<ul style="list-style-type: none"> Difficult to keep head upright against gravity, may prop head in hand Can't process rotation - the stimulation from swinging or going in circles with the walker is probably more visual than vestibular Contributes to problem with Balance

***NOTE**
Cranial nerve VIII is also called the "Auditory" nerve.

Balance

The **visual**, **vestibular**, and **proprioceptive** systems work together to enable us to achieve upright balance and to maintain it as we move through space. Postural control relies primarily on these three systems functioning well **TOGETHER**.


Balance in CHARGE



Vision **Prop.**

- Vestibular:** little or none
- Vision:** impaired
- Proprioception:** impaired

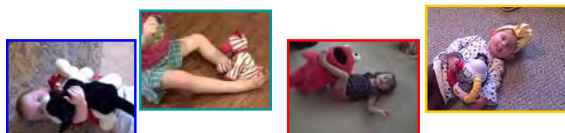
Walking occurs against all odds!



- Walking emerges later than for typically developing children.
- It takes **a lot of energy to stay upright**, so many children with CHARGE Syndrome need some literal "down time" lying down on their backs. **They are NOT LAZY. They are EXHAUSTED.**

What does this mean for a child?

- The child with CHARGE experiences the world differently from the way others do.
- He faces **ENORMOUS** challenges in perceiving (taking in and “making sense” of sensory inputs) and responding to (motor output) just about every Life Experience he encounters.



What does it mean for us?

- We, as parents, educators and service providers, face an enormous challenge as well.
- To help a child develop the **skills** (which are a kind of “**motor output**”) he or she needs to live the most meaningful, productive, enjoyable life possible, we must first **recognize and respect** those differences in “**sensory input**” that define the child’s experience of Self and Self in relation to the environment.

References and Resources

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Sensory system graphics are from a number of online sources.

What’s Next?

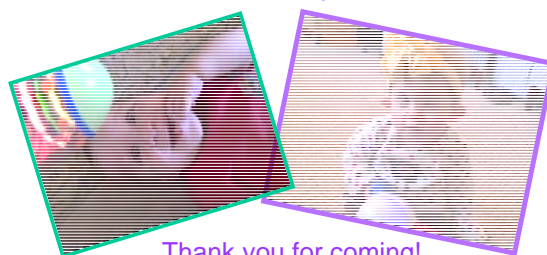
How will increased awareness of the unique and complex sensory issues in CHARGE Syndrome influence our expectations about behavior, and the types of interventions we employ?



Self-Portrait by
Andrew Hippenstiel

Let’s wrap it up.

Evaluations, please.



Thank you for coming!



Category: Family Support

Saturday
Breakout Session #8:44: 3:30-4:30
Palomino 10

Family Leadership and
Collaboration

Kimberly Lauger, RN

Consultant
Arizona Deafblind Project

Presenter Information:

Kimberly Lauger, RN, began her studies of neurodevelopmental difficulties in order to meet the needs of her own children. Kim has one son who struggled with attention and learning difficulties, one son with CHARGE Syndrome and vision and hearing loss, and a daughter for whom learning and “being” is relatively easy. Kim’s professional background includes the fields of pediatric nursing, developmental disabilities, foster parenting, behavioral science, deafblindness, neurodevelopment, and healing touch. Kimberly works as a consultant and intervener trainer for the Arizona Deafblind Project and is owner of the Redtail Neurological Center.

Presentation Abstract:

This workshop is geared to helping families develop collaboration and leadership skills. It will include an emphasis on positive team building, tips for presenting information verbally and in writing so their message is heard. Using the topic of Interveners as an example, participants will work together to create a plan to share information with others about this topic.

Family Leadership and Collaboration
Kimberly Lauger, RN

This workshop is geared to helping families develop collaboration and leadership skills. It will include an emphasis on positive team building, tips for presenting information verbally and in writing so their message is heard. Using the topic of Interveners as an example, participants will work together to create a plan to share information with others about this topic.

This session is highly recommended for Arizona families receiving funds from the Pilot Parents LEAP grant and other families wanting to build collaborative networks and strengthen their advocacy skills.

This will be an interactive rather than “formal presentation” session and will be based on the needs of the participants.

We will explore topics like:

I have so much new information from the conference, but what do I do with it?

How can I communicate with my child's medical and educational teams so they understand my child?

How do I write an effective advocacy letter to legislators or school officials?

I've always been shy, what are some tips for sharing our story and getting my child's needs met?

How can I work together with other families to make changes to the laws that influence my child's well-being?



Category: Parent Share
Adult Issues

Saturday
Breakout Session #8:45: 3:30-4:30
Dorado

“Parent Share”
Adult

Betsy Bixler, M.Ed.
Deafblind Education
Perkins Training Center
Perkins School for the Blind
Watertown, MA 02472

Presenter Information:

Betsy is currently the Manager of Perkins Training Center, a professional development and continuing education program that provides lectures, workshops and courses to professionals and family members working with and on behalf of students with visual impairment and deafblindness. Included in the training plan conducted by the Perkins Training Center, are workshops and lectures that address critical topics that impact children with CHARGE syndrome.

Presentation Abstract:

This is the fourth of four facilitated sessions conducted for parents, each with an individual focus on the topics of: Behavior, Education, Adult Services and Medical.



Category
Fundraising

Saturday
Breakout Session #8:46 3:30-4:30
Moor 2

**Fundraising: Big or Small We
Love it All**

David Wolfe
President, CHARGE Syndrome Foundation

Presenter Information:

David became the Fundraising Chair for the Foundation since joining the board in 2008. He has served on the Executive Committee since 2009, first as Treasurer and currently as President. One of his many jobs includes an ongoing effort to encourage and work with families, individuals and groups to advance the vision and mission of the Foundation through a variety of fundraising efforts.

Presentation Abstract:

This interactive session will focus on the critical importance of fundraising for the ongoing success of the Foundation. We will highlight some interesting events and explore ways for everyone to get involved. We will also discuss the growing use of technology in fundraising as well as the more traditional approaches. Whether you are an experienced fundraiser looking to tweak your approach, or a novice looking to begin the process, this session will provide useful information. Bring your ideas, enthusiasm and questions. It Can Be Done!

FUNDRAISING FOR CHARGE

Big or Small
We Love it All



MY TOP 3 LIST

3) Fundraising takes too much time



FUNDRAISING IS NECESSARY

- No non-profit survives without fundraisers
- Fundraising is NOT evil!
- Fundraising is NOT begging!
- Fundraising is critical to the success of EVERY non-profit.

MY TOP 3 LIST

■2) I don't know many rich people



Fear

MY TOP 3 LIST

■ I don't like asking for money



Fundraising is about _____?

BIG AND SMALL

- Not every event has to raise huge dollars at one time. It is far better to do something small than nothing at all.
- Many people feel that if they can't host a run, walk, or gigantic event it is simple not worth doing. **That is simply not correct!**
- Donation cans
- Garage sales
- Bake sales
- Sell awareness items
- March madness
- Superbowl squares

MY SIMPLE ADVICE

Pursue your passion

Almost anything can be turned into a fundraiser. Be creative and choose something you enjoy.

THE ADD ON: INCREASE THE REVENUE FROM YOUR EVENT

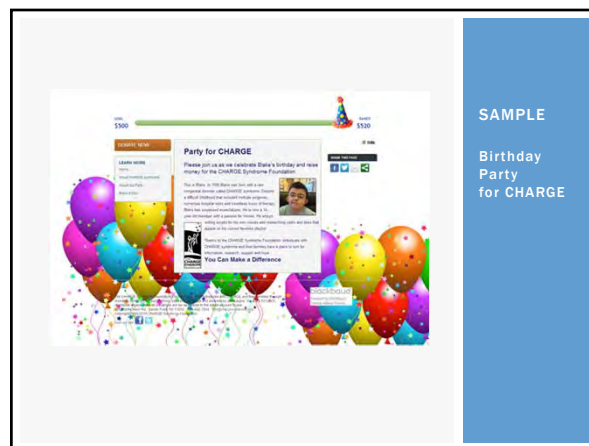
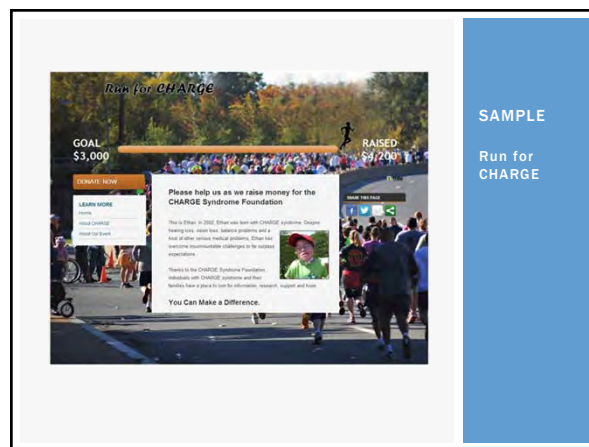
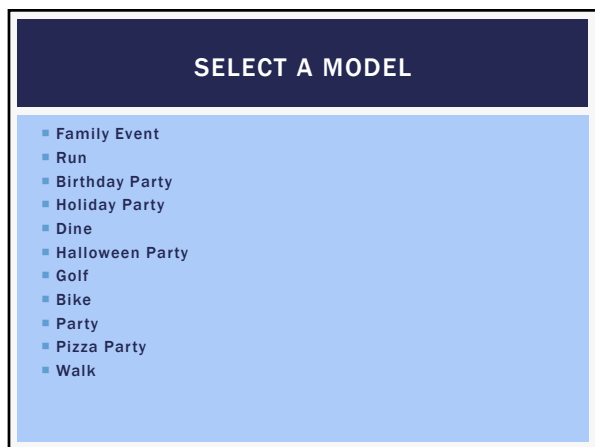
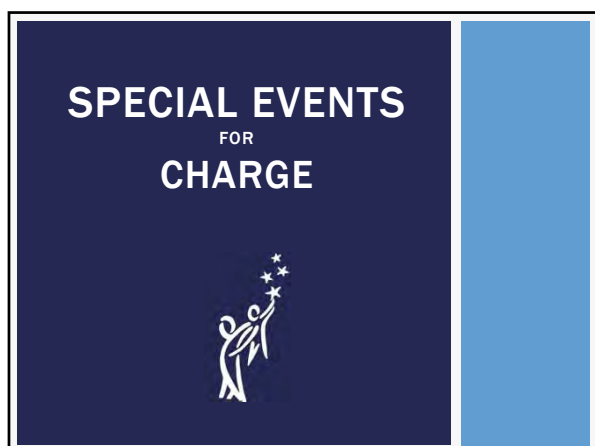
- Take a traditional event and supplement with online capabilities
- Have things to sell
- Have some type of auction
- Have some type of raffle

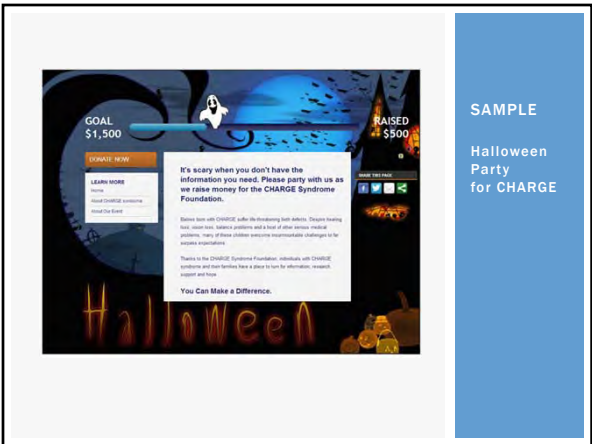
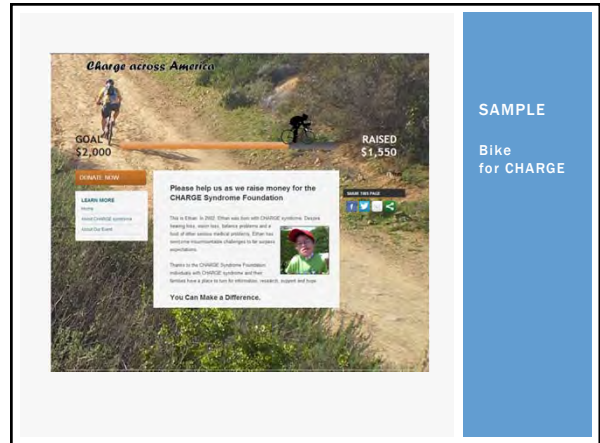
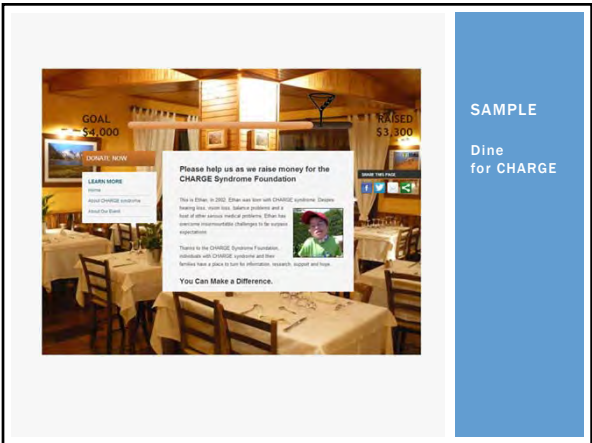
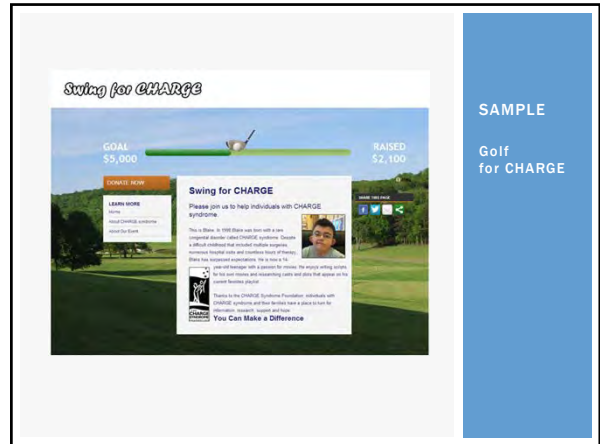
PLAN

- Take a realistic look at how much time you have to spend on an event
- Figure out how much help you will have
- Budget
- Execute

ONLINE FUNDRAISING

- * Can be stand alone or combined with events
- * Charge It for CHARGE
The Foundation has raised over \$400,000 using our Charge It for CHARGE templates.
- * A tailored page for special events:
 - Provides an easy way to collect funds on-line
 - Makes it easy for people to donate even if they can't attend
 - Tracks your goal and progress







pile on the Fun for CHARGE

GOAL \$500 RAISED \$475

Party for CHARGE

Please join us for pizza as we celebrate Shelia's birthday and raise money for the CHARGE Syndrome Foundation.

This is Shelia. In 1998 Shelia was born with a rare congenital disorder called CHARGE syndrome. Shelia is a vibrant, intelligent, and curious young woman who has overcome many challenges. She has a passion for music and dance, and she is currently studying for her degree in Music Business at the University of North Carolina at Charlotte. Shelia has a special talent for making people laugh and she is always ready to help others in need.

Thanks to the CHARGE Syndrome Foundation, individuals with CHARGE syndrome and their families have a place to turn for support, resources, support and love.


You Can Make a Difference

SAMPLE

Pizza Party for CHARGE

TURN AN OCCASION INTO A FUNDRAISER

- Select a model from our samples
- Name your event
- Set a goal
- Provide a favorite photo
- Provide text about your special individual with CHARGE
- Provide text about your event
- We'll create a special webpage for your event
- Use your webpage to help raise money and awareness for the CHARGE Syndrome Foundation



Walk for CHARGE

GOAL \$5,000 RAISED \$4,500

Walk with us as we raise money so that the CHARGE Syndrome Foundation can help families and individuals with CHARGE.

All proceeds go to the CHARGE Syndrome Foundation.

This is Shelia. In 1998 Shelia was born with a rare congenital disorder called CHARGE syndrome. Shelia is a vibrant, intelligent, and curious young woman who has overcome many challenges. She has a passion for music and dance, and she is currently studying for her degree in Music Business at the University of North Carolina at Charlotte. Shelia has a special talent for making people laugh and she is always ready to help others in need.

Thanks to the CHARGE Syndrome Foundation, individuals with CHARGE syndrome and their families have a place to turn for support, resources, support and love.

You Can Make a Difference

SAMPLE


Walk for CHARGE

THE THANK YOU

Thank your volunteers

Thank your donors

Thank them all again



Create a Title

Help Finley Reach for the Stars

GOAL \$5,000 RAISED \$4,705

Support Finley's Fundraiser

Please party with us as we raise money for the CHARGE Syndrome Foundation.

This is Finley. In 2002 Finley was born with a rare congenital disorder called CHARGE syndrome. Finley is a vibrant, intelligent, and curious young woman who has overcome many challenges. She has a passion for music and dance, and she is currently studying for her degree in Music Business at the University of North Carolina at Charlotte. Finley has a special talent for making people laugh and she is always ready to help others in need.

Thanks to the CHARGE Syndrome Foundation, individuals with CHARGE syndrome and their families have a place to turn for support, resources, support and love.

You Can Make a Difference

Set a Goal

Provide Details about your Event and Individual with CHARGE

Provide a Photo and brief Text about your Event and Individual with CHARGE

WHAT YOU PROVIDE

We create your special webpage

Use your event to raise money and awareness for the Foundation