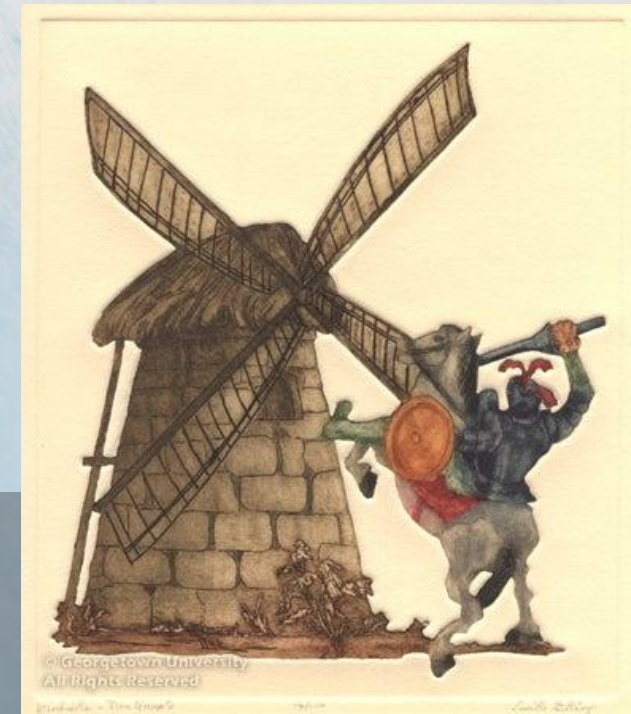


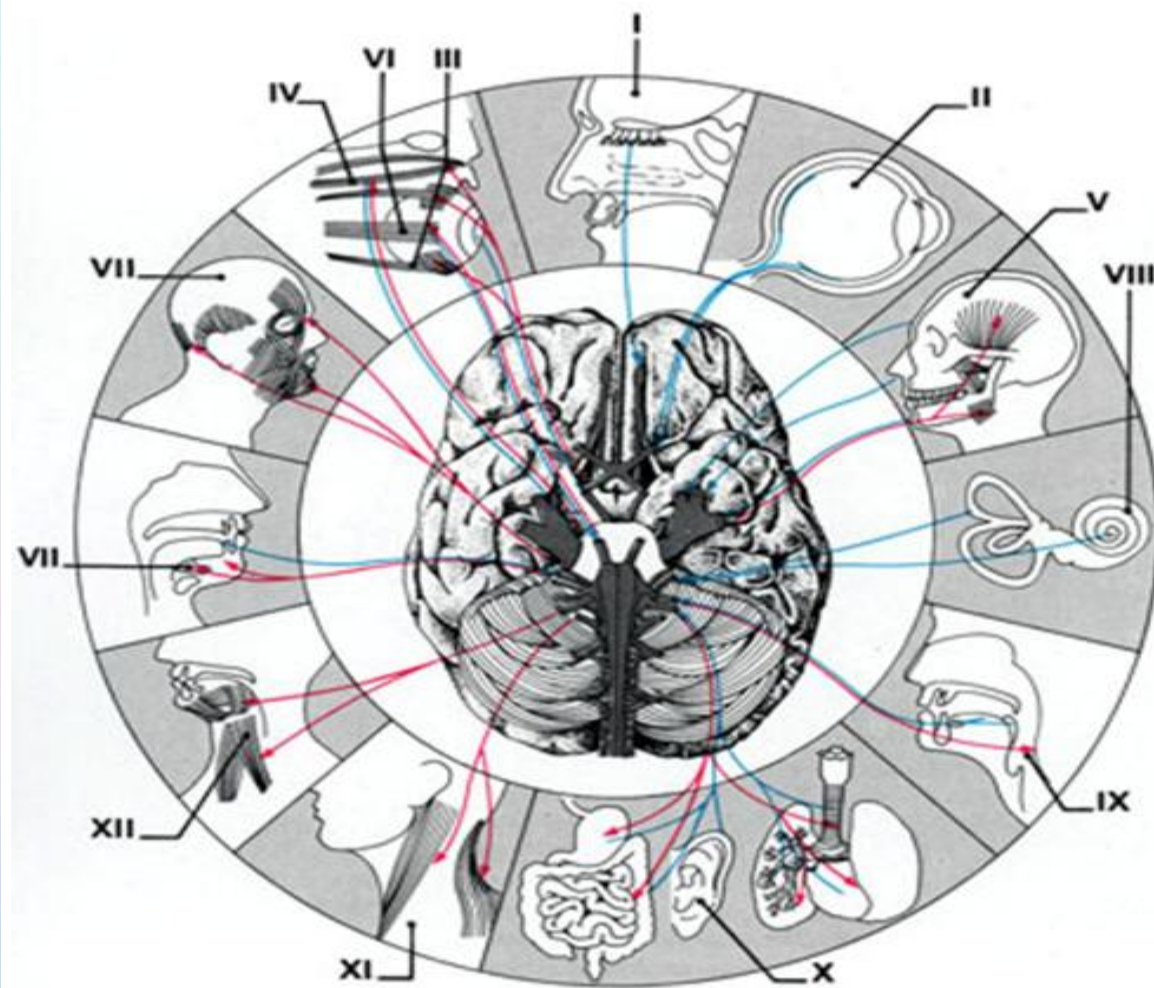
CP State

7th Annual Conference on Multi-Disciplinary Clinical Care for Patients with Intellectual and Developmental Disorders (I/DD)

TILTING AT WINDMILLS: THE
ROLE AND TRIBULATIONS OF
THE CLINICIAN ADVOCATE IN
THE I/DD ARENA

Rick Rader, MD, FAAIDD, FAADM, DHL (hon)
Director of Habilitation Center, Orange Grove Center





CRANIAL NERVES

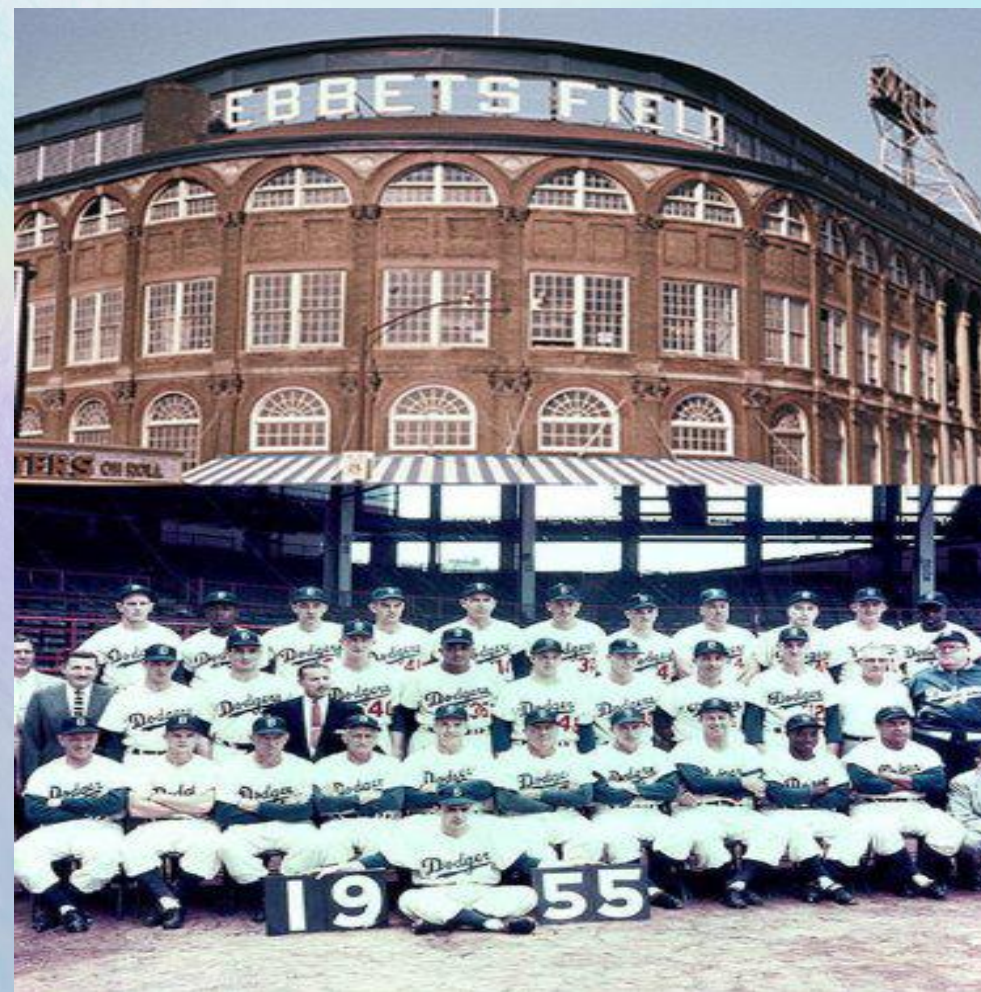








HELLO FROM
CHATTANOOGA, TN





Formula 1 L'Equip MATRA
1972



**The Kennedy Home for Handicap
Children in St. George Grenada
1979**





1982

March 15, 1982

Dear Rick,

It was a pleasure to have you on our service. Before you leave, be sure to check out the FLKs on Eleanor East.

Sincerely,

R. W. Braithwaite, MRMCPCH
Chief Paediatrics Registrar
GOSHC



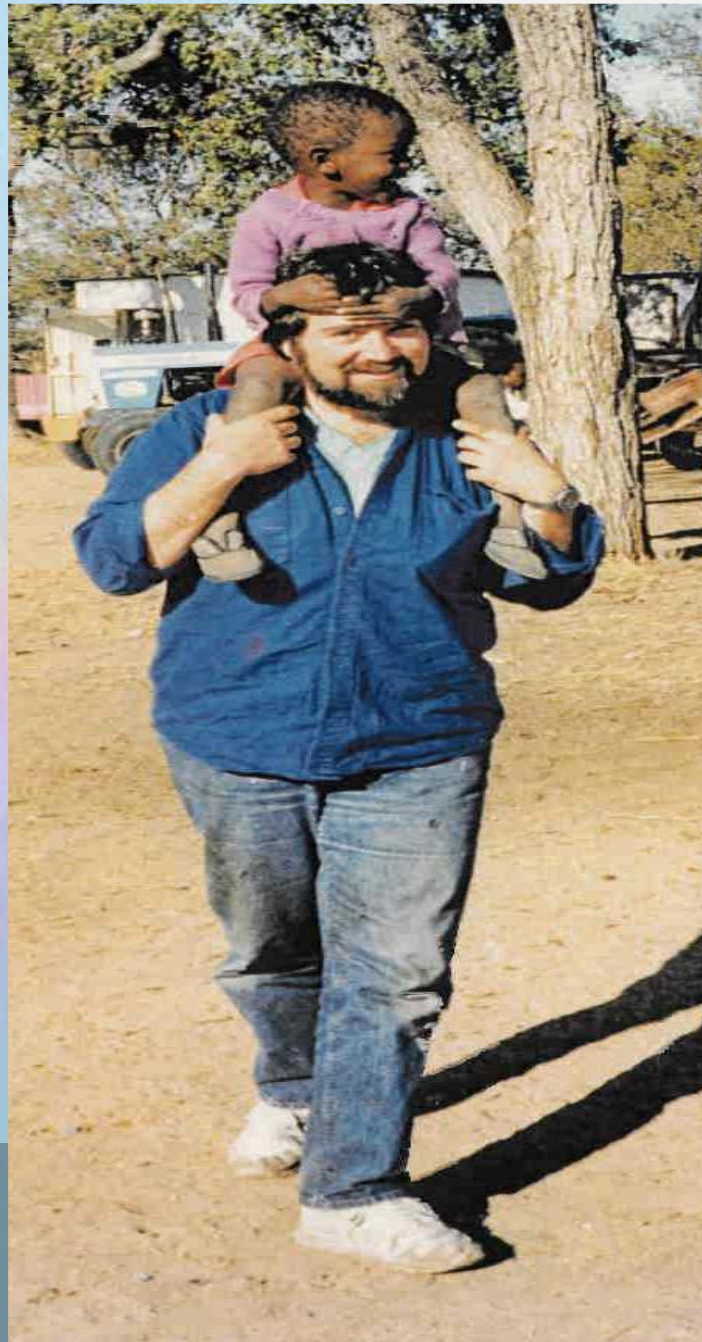
**JOHN IS A SPASTIC-
he needs your help!**

You'd love John. He's six years old and, like all small boys, mischief twinkles in his eyes. But John is a spastic. He desperately needs the care and training we can give him and thousands of children like him. Will you join us in getting John on his feet? Just put whatever you can spare in an envelope and post it to this address now: THE SPASTICS SOCIETY, 12 PARK CRESCENT, LONDON, W.1.



alamy - DE3AQ





Kingdom of Swaziland
1986

JAMA[®]

The Journal of the American Medical Association

December 1, 1993

Professional & Technical

SEEKING AN EXTRAORDINARY PROFESSIONAL FOR A leading private, non-profit, non-institutional, non-governmental center. Our center serves mentally handicapped and medically fragile individuals and has been a pioneer for over four decades in methodology, programming, and facility, to economically improve the lives of its clients. Today a new generation of service is requisite to continue in the forefront of these endeavors. We seek an imaginative, aggressive, inventive individual who can, as required, develop and lead cooperative research, implementation, cross discipline involvement (including perhaps but not limited to staffs of our local universities, national pharmaceutical companies, medical professionals, computer companies, etc) Our new Habilitation center, scheduled to be completed in December 1993, is built for the new generation of service. Currently, our facilities also include 26 residences with 15 additional funded and to be built, an Educational Facility, workshop and vocational training facility, a major recycling center, work development and placement facility, and a full range medical and Therapeutic service unit. Please send letter of interest with resume to PO Box 2491, Chattanooga, TN 37409.

... A NEW sales
... needs protection device
... 60145 Mon-Thurs 7-8
WANTED
If you're a parent of a
mentally retarded child please call.
Help needed in starting a school for
handicapped and crippled kids.
Call MADISON 37201
... natural selling talent
... salary, a perc
... merous store
... able in o







**We don't care
how you did it
in New York.**



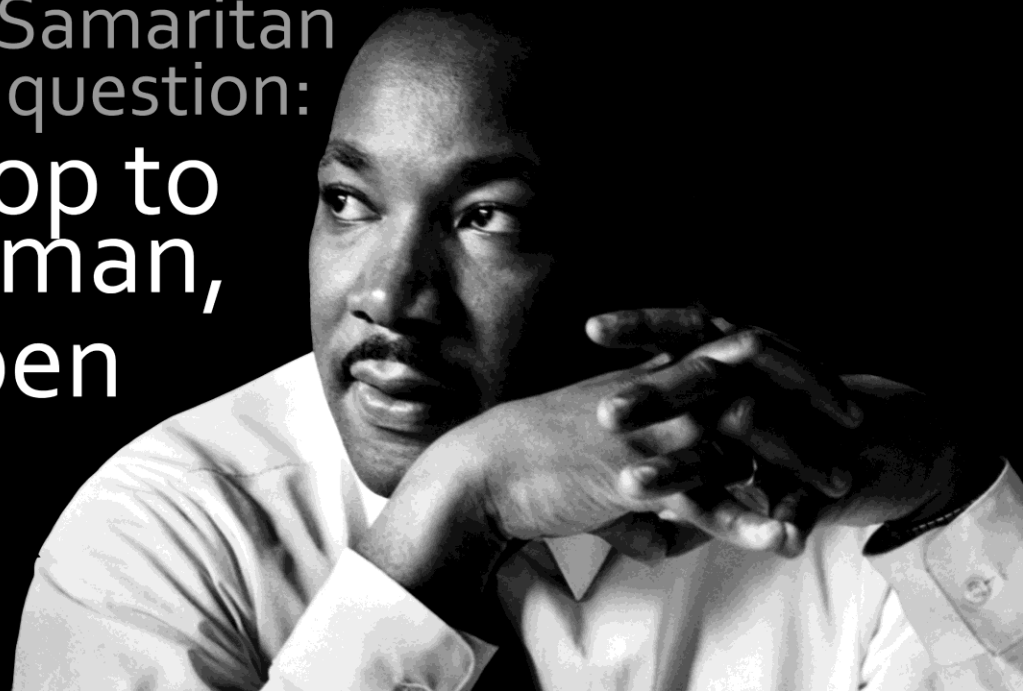
**LEARNING
FROM OUR PATIENTS**


The first question which the priest and the Levite asked was: **If I stop to help this man, what will happen to me?**

But... the good Samaritan reversed the question:

If I do not stop to help this man, what will happen to him?

- Martin Luther King Jr.





Survey of people over 95 were asked:
"If you had to live your life over again what would ~~not~~ do differently?"

1. Reflect more
2. Take more risks
3. Do more things that someone else thought were worthy of carrying it on.



Your New Health Care System

Legend:

- New Government:**
 - Red circle: Retaining Potential
 - Orange circle: Transitioning to Health Insurance Market
 - Blue circle: Other Expenses
 - Green circle: Representative Bodies of Additional Entities
- Expanded Government:**
 - Yellow circle: Government with Expanded Authority/Responsibility
 - Light blue circle: Government Financial Entry with New Incentives/Outcomes
 - Light green circle: New/Temporary with Expanded Authority/Responsibility
- Private:**
 - Dark blue circle: Private Entry with New Mandates/Regulations/Responsibilities
 - Light blue circle: Outgrowth
 - Light green circle: New Entry
 - Light blue circle: Consolidation/Integration/Spin-Off
 - Light green circle: Special Interest Provision
- New Relationships:**
 - Red circle: Regulation/Regulatory Mandates
 - Orange circle: Reporting Requirements
 - Blue circle: Oversight
 - Green circle: Money Flow
 - Yellow circle: Consolidation/Integration/Spin-Off
 - Light blue circle: Special Interest Provision

Key Entities and Connections:

- President:** Connected to the Secretary of Health & Human Services and the Congress.
- Congress:** Connected to the President and the Secretary of Health & Human Services.
- IRS:** Connected to the Treasury Department and the Secretary of Health & Human Services.
- Treasury Department:** Connected to the IRS and the Secretary of Health & Human Services.
- Social Security Administration:** Connected to the Secretary of Health & Human Services.
- PCORI:** Connected to the Secretary of Health & Human Services.
- CMS:** Connected to the Secretary of Health & Human Services.
- Medicare:** Connected to the CMS and the Secretary of Health & Human Services.
- Medicaid:** Connected to the CMS and the Secretary of Health & Human Services.
- Private Health Insurance:** Connected to the Secretary of Health & Human Services.
- Physicians:** Connected to the Secretary of Health & Human Services.
- Patients:** Connected to the Secretary of Health & Human Services.

Patron: Protection & Affordable Care Act, P.L. 111-148.
Health Care & Education Reconciliation Act, P.L. 112-10.
Prepared by Joint Economic Committee, Republican Staff
Congressional Events Study, Senior House Republican
Senator Sam Brownback, Ranking Member

**The first step to getting anywhere is deciding
you're no longer willing to stay where you are.**



ADVOCACY:

A broad-based analytical approach to problem solving designed to protect personal and legal rights, and to insure a dignified existence
The deliberate process of influencing those who make policy decisions!





Amelia



"We don't waste
organs on those
kind of kids"



"As an organization, we regret that we communicated in a manner that did not clearly reflect our policies or intent and apologize for the Riveras' experience. We are completely committed to the careful review of our processes and written material to ensure that we are sensitive to the needs of all families, including the specific needs of families of children with disabilities. While we can unequivocally state that we do not disqualify transplant patients on the basis of intellectual ability, and have a history of transplanting children that have a wide range of disabilities, this event underscores the importance of our responsibility to effectively communicate with families. We appreciate the role the Riveras have played in helping us recognize opportunities to improve our communication,"
Michael Apkon, MD, senior vice president and chief medical officer at The Children's Hospital of Philadelphia.

CHOP ISSUES APOLOGY

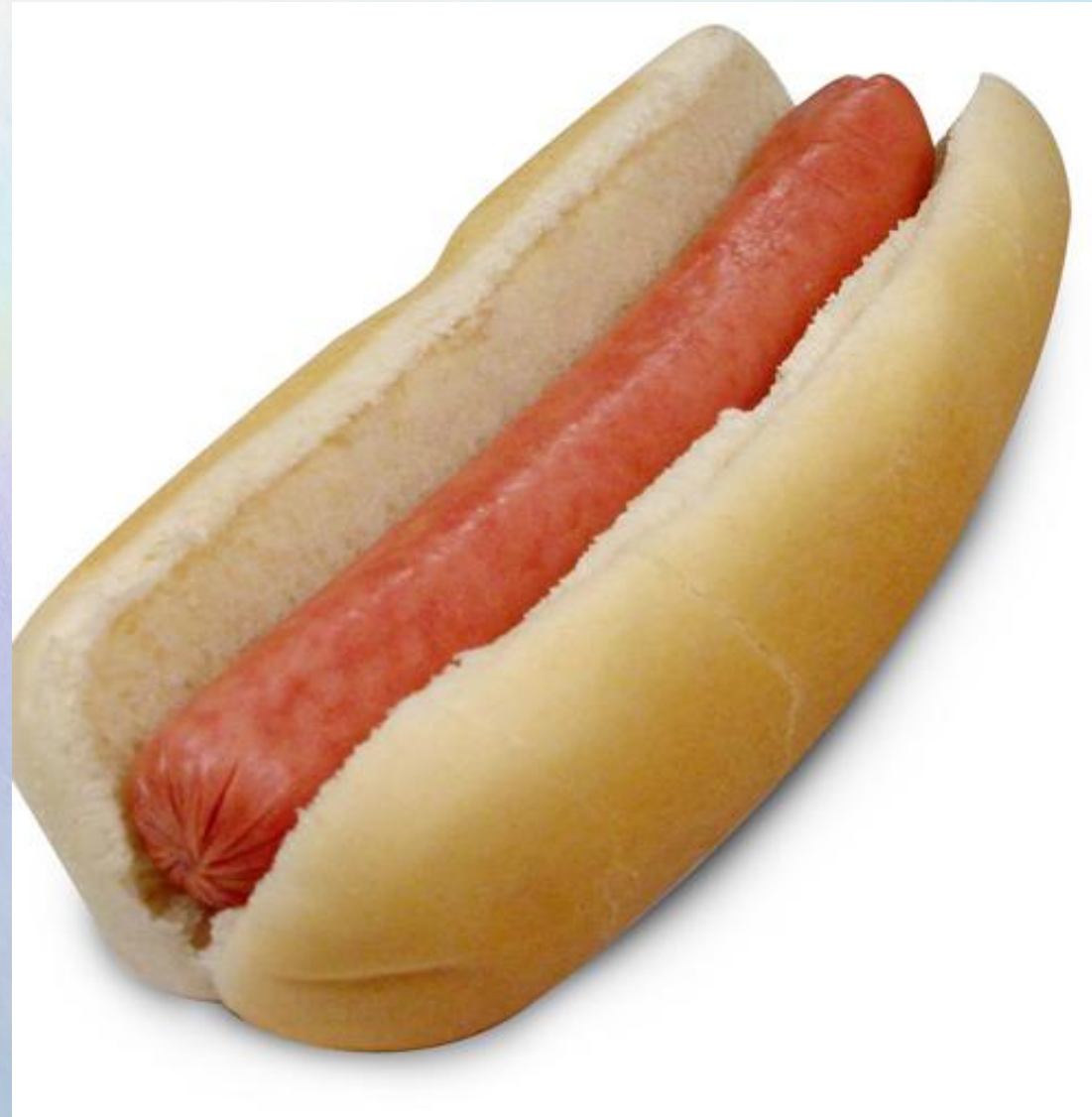


Amelia and Mom awaiting transplant



ADVOCACY ACTION STEPS

- *Define the issue
- *Get the facts
- *Develop an action plan (goals and objectives)
- *Develop and Deliver the Message
- *Monitor and evaluate progress
(evaluate your successes & misses!)









**Head Doc @ Tennessee Department
of Intellectual and Developmental
Disabilities**

The Nursing Board





The Pharmacy Board

The Medical Board













Tell Your Story!

- *Humans respond to human stories!
- *Every story teaches others
- *Concentrate on lessons learned from your experience
 - *Give enough background so others can feel what you experienced







Tennessee Newborn Screening Profile 2000

- * PKU
- * Congenital Hypothyroidism
- * Galactosemia



A LITTLE MORE THAN THREE...

Fatty Acid Oxidation Disorders

2,4 Dienoyl-CoA reductase deficiency (DE RED)
Carnitine acylcarnitine translocase deficiency (CACT)
Carnitine palmitoyltransferase I deficiency (CPT-IA)
Carnitine palmitoyltransferase type II deficiency (CPT-II)
Carnitine uptake defect (CUD)
Glutaric acidemia, type II (GA-2)
Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
Short-chain acyl-CoA dehydrogenase deficiency (SCAD)
Trifunctional protein deficiency (TFP)
Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

Hemoglobin Disorders

Hemoglobinopathies (Var Hb)
S, Beta-thalassemia (Hb S/ β Th)
S, C disease (Hb S/C)
Sickle cell anemia (Hb SS)

Organic Acid Conditions

2-Methyl-3-hydroxybutyric acidemia (2M3HBA)

Amino Acid Disorders

Argininemia (ARG)
Argininosuccinic aciduria (ASA)
Benign hyperphenylalaninemia (H-PHE)
Biopterin defect in cofactor biosynthesis (BIOPT-BS)
Biopterin defect in cofactor regeneration (BIOPT-REG)
Carbamoyl phosphate synthetase I deficiency (CPS)
Citrullinemia, type I (CIT)
Citrullinemia, type II (CIT II)
Classic phenylketonuria (PKU)
Homocystinuria (HCY)
Hypermethioninemia (MET)
Hyperornithine with gyrate deficiency (Hyper ORN)
Maple syrup urine disease (MSUD)
Nonketotic hyperglycinemia (NKH)
Tyrosinemia, type I (TYR I)
Tyrosinemia, type II (TYR II)
Tyrosinemia, type III (TYR III)
Endocrine Disorders
Congenital adrenal hyperplasia (CAH) Primary congenital hypothyroidism (CH)







SCREENED AND SAVED





Getting invited to the castle vs storming the castle:

- Know the decision-makers and what motivates them
- Position the decision-makers to receive the applause
- Stay informed - the landscape is a moving target
- Stay connected - legislative staffers are often reassigned
- Use every opportunity to learn and share information about the "cause."

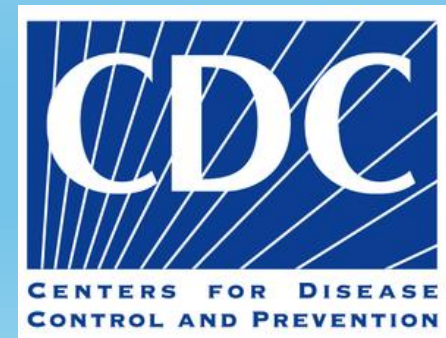


Designated Priority Populations

2009 CDC H1N1 Flu Pandemic High Risk Populations – Anticipated Vaccine Shortages

- **Children younger than 5, but especially children younger than 2 years old**
- **Adults 65 years of age and older**
- **Pregnant women**
- **People who have medical conditions including:**
- **Neurological and neurodevelopmental conditions [including disorders of the brain, spinal cord, peripheral nerve, and muscle such as cerebral palsy, epilepsy (seizure disorders), stroke, intellectual disability (mental retardation), moderate to severe developmental delay, muscular dystrophy, or spinal cord injury].**

**Dropped from the list..
adults with ID/DD!!**





Incremental Success: Start with Small Bites

- *Comprehensive change often require perfect alignment of multiple variables including luck
- *A series of small success makes the process manageable and less daunting







International **TO BAN** CAMPAIGN LANDMINES

1997 Nobel Peace Prize Co-Laureate



A global network in some 100 countries
Working for a world free of landmines

The HEADs UP Act of 2018

**for those with intellectual
and developmental disabilities**



MUP

MUP

ENDORSED BY:

- *American Medical Association
- *American Dental Association
- *American College of Physicians
- *National Council on Disabilities
- *Presidents Committee
- *American Public Health Association
- *American Academy of Pediatric Dentistry
- *American Association on Health & Disability
- *Yada, Yada, Yada



Covid19 Pandemic



The game changer

Covid19 Pandemic



The AADMD Advocacy Machinery Kicks In!

Covid19 Pandemic



**Direct Support Staff Permitted to Accompany
Patients in the Hospital!**

Covid19 Pandemic



The AADMD Advocacy Machinery Kicks In!

Covid19 Pandemic



AADMD Policy
Paper Initiates
Office of Civil
Rights to Insure
Equity



**INSIDER
TRADING**



Every normal man must
be tempted at times to
spit on his hands, hoist
the black flag, and begin
to slit throats.

H.L. Mencken







Project D.I.M.E.



“Preparing Clinicians
to Provide Competent
Care to Patients with
Disabilities”