

~~Disease Distribution, Diagnostic Services and Approach to Care~~

New Leaf Clinic
Mount Eaton, Ohio
Olivia Wenger, MD

A Little Mennonite Girl's Guide to Starting a Clinic for Special Children

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Five guidelines for the new recruits...

1) Don't let your CSC idols get you down.



Reach out to people who have the training, skills and perspective you lack.



Remember, learning was difficult for them, too.

2) It always helps to have a flexible spouse.



But spouses come at their own risk.



You may find yourself in front of a room full of Amish bishops while 8 months pregnant

3) Don't rely on your intern's GPS.



4) Always pack a spare tire.



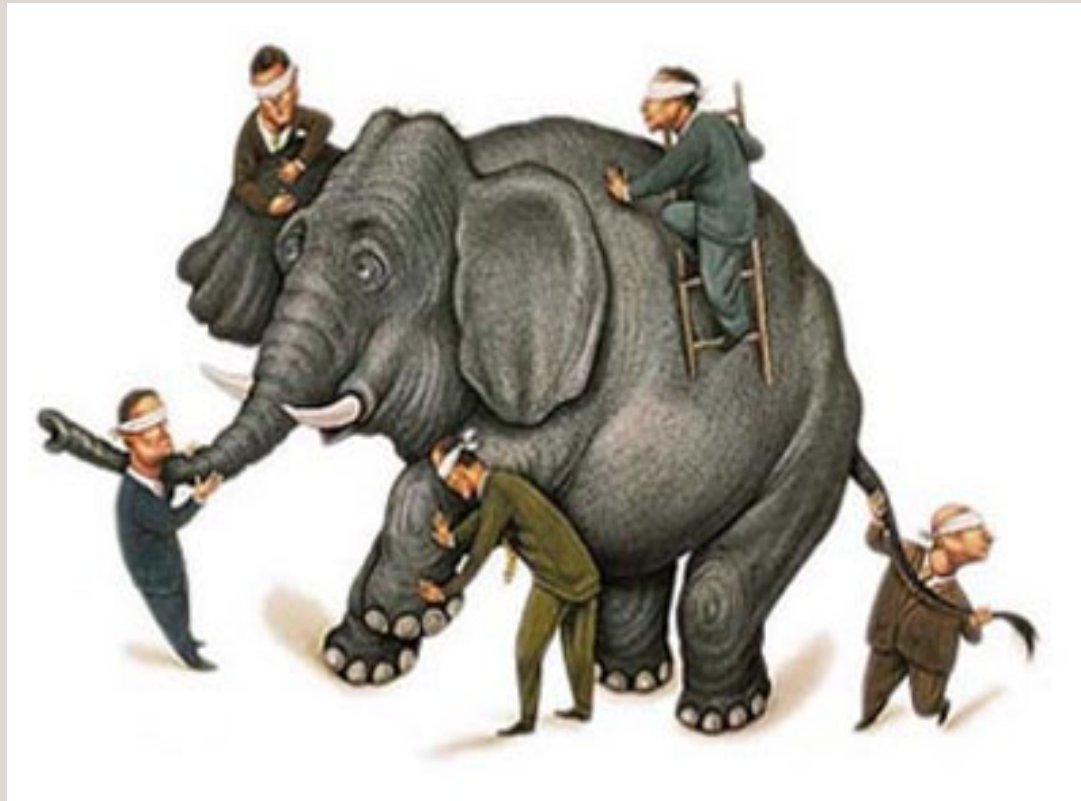
*Insert Flexible spouse here. If not in stock, get AAA.

5) Buy a bag of doggy treats.



AND pepper spray...

Holmes county, Ohio: The blind men & the elephant?



Holmes county, Ohio



Population History

- *Matches Lancaster county settlement in size
- *Settlement is genetically distinct from Lancaster county
- *Genetic connection to Western Pennsylvania population
- *Isolate within isolates:
 - church splits led to higher risk for specific recessive conditions within various Amish orders
 - ie, “Swartzentruber” vs. “Dan” vs. “Old Order”
 - most traditional/low order Amish do not typically affiliate with more progressive orders
- *Most progressive orders have organized financial/church resources to deal with healthcare costs
 - ie, Ohio Crippled Childrens Fund

New Leaf Timeline

Akron Childrens Hospital: exploratory work 2010 to 2013

DDC Clinic: monthly outreach clinics to Holmes county area

Windows of Hope: research

August 2011: preliminary proposal

-DDC, Dept of Health, ACH, OCCF, Windows of Hope boards.

January 2012: steering committee

Jan/Feb 2012: Board formation

March 2012: Community meetings

March-July 2012: Fundraising

January 2013: clinic opens

New Leaf Clinic History

Board structure:

- 50% Amish
- 50% English

Funding:

- independent non-profit
- physician employed by Akron Childrens Hospital
- physician salary/benefits/insurance covered 50% by clinic
- all other initial funding from individuals, businesses, churches
- all billing for services rendered belongs to New Leaf Clinic
- Goal: 25% of operating budget based on patient fees

Advisory Board:

- Bishops from each Amish order in Wayne/Holmes county area

New Leaf Clinic Opened January 2013



NEW LEAF
CENTER 

CLINIC FOR SPECIAL CHILDREN

Current Knowledge Survey: Four sources

1) **Akron Childrens Hospital:** EMR query

*based on ICD-9 codes/surname/demographics

2) **DDC:** Disease incidence prediction

*based on carrier frequency

*based on current patient population

3) **CSC:** Disease incidence prediction

*based on carrier frequency

*based on counties/geographic patient distribution

4) **Windows of Hope:** Disease incidence prediction

*based on carrier frequency

*based on church group/order

NLC Disease distribution : Neurodevelopmental Disorders (Total=56)

Neurodevelopmental	
GM3 Synthase Deficiency	7
Hershberger syndrome	7
SAMS association	6
Yoder dystonia	3
Familial Macrocephaly/DD	3
Familial Absence seizures	2
Other DD/social delays/ hypotonia	2
Dystonic cerebral palsy/DD	1
Other DD/social delay	1
Epilepsy	1
<i>Blue eye delay/HERC2</i>	
<i>Troyer syndrome</i>	
<i>Mast syndrome</i>	

NLC Disease Distribution: Other Disorders (T=56)

Metabolic	
Propionic acidemia	12
Glycogen Storage Disease, Type 1	2
<i>Cobalamin C deficiency</i>	
<i>Prolidase deficiency</i>	
<i>PKU</i>	
Cardiac	
Long QT syndrome (?)	1
<i>MYBPC3</i>	
Pulmonary	
Cystic Fibrosis	3
GI	
Biliary Atresia	1
Musculoskeletal/Dysplasias	
Cartilage Hair Hypoplasia	4
<i>MOPD</i>	
<i>Cockayne</i>	
<i>Osteopetrosis</i>	

Diagnostic Services: RY Case Study

CC: 5 month old female from “Dan” Amish with poor visual tracking, hypotonia, and odd tongue movements.

Birth: G3P2 28 year old Mom, term SVD at community hospital. Left nursery at 3 days of life. Newborn screen WNL. Fussy in newborn period.

Diet: Not able to sustain breastfeeding

Dev: Coos, cries, but does not vary tone of voice. Smile is not reciprocal. Grasps toys. Does not roll. Requires more head/back support than most five month olds. Parents main concern is lack of visual tracking. Pt responds to light, but not faces. They deny nystagmus.

Diagnostic Services: RY Case Study

PE:

Growth parameters in 25-50th percentile

Gen: Fussy, soothed by parent's touch. No smile

HEENT: Non-dysmorphic. Pupils reactive. Does not track.

CV/Resp: WNL

Abd: Soft, no HSM

GU: Normal female

Neuro: Normal muscle bulk

Hypotonic

Reflexes 1+

?Dystonic tongue movements

Diagnostic Services: RY Case Study



Approach to Care: RY Case Study

Differential Diagnosis:

Yoder Dystonia

Hershberger syndrome

TMCO1

Other (metabolic disorder)

Other (space occupying lesion)

My approach:

--Peds Optho eval at Akron Childrens Hospital

--rule out Yoder Dystonia/TMCO1

--rule out Hershbergers

--further workup as needed

Special Children not only teach us compassion, they ask us to work together. They ask us to set aside academic tensions, church conflicts and personal pride in order to offer them the best care possible.

