



**The Community  
Health Clinic**

# *Identifying Needs, Implementing Services in the Indiana Plain Community*

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The Indiana Hemophilia & Thrombosis Center  
*Board of Directors*  
The Community Health Clinic

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*Genetic Counselor*  
The Indiana Hemophilia & Thrombosis Center  
The Community Health Clinic

*A Place for Our Special Children*

# The Indiana Plain People

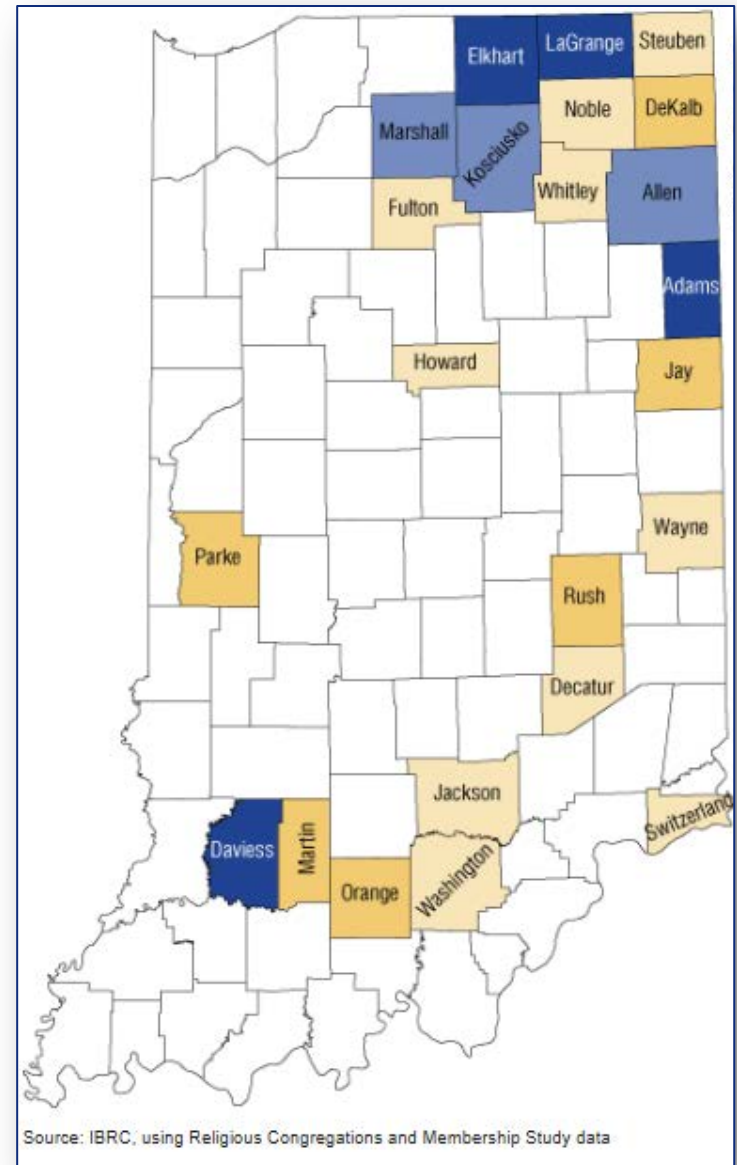
## □ Indiana

- 47,235 Amish Individuals
- 22 settlements

## □ 3rd largest Amish settlement located in northern IN

- Elkhart and LaGrange counties contain 21,560 Amish individuals

## □ Mennonites in the area as well





# HTC Comprehensive Model of Care

- Non-profit/mission driven**
- Multidisciplinary**
  - Physician, PA/NP, Nurse(s), Physical Therapy, Social Workers, Dietitian, Dental Hygiene, Genetic Counseling, Risk Reduction, Research, Career Counseling
- Family/patient centered**
- Part of national network of 140 centers**
- Public Health Service pharmacy funded**

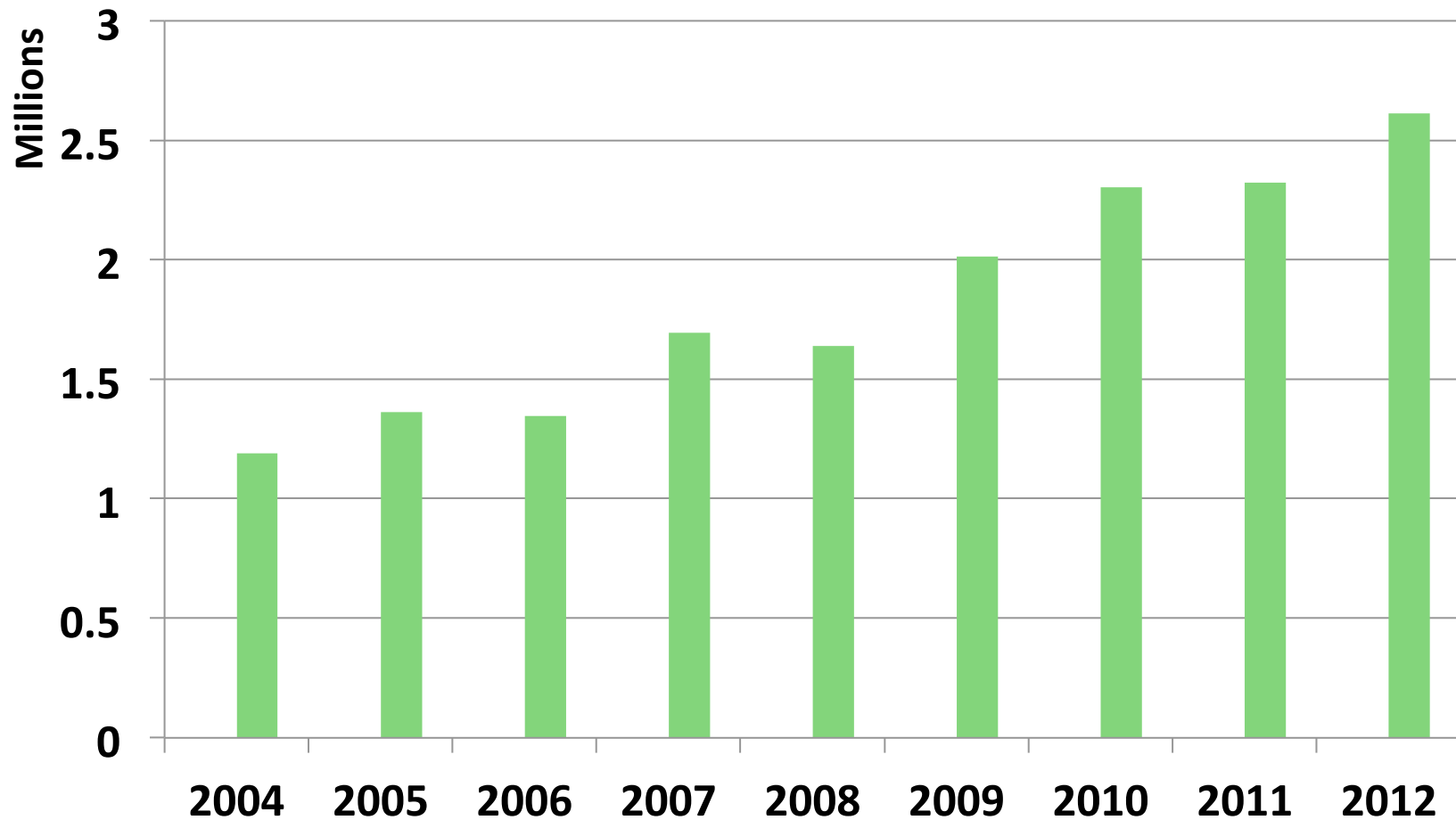
# Amish patients with bleeding disorders

Diagnosis	# Amish patients
Factor IX deficiency	48
Factor VIII deficiency	2
VWD Type 1	15
VWD Type 2M	74
PAI-1 deficiency	11
Factor IX low level carrier	22
Factor IX non-low level carrier	50
Factor VIII low level carrier	1
Factor VIII non-low level carrier	8

# Amish bleeding disorder mutations

- ❑ **FIX deficiency (XL)**
  - 31008 C>T
- ❑ **FVIII deficiency (XL)**
  - Intron 22 inversion
- ❑ **VWD 2M (AD)**
  - 4120 C>T
- ❑ **VWD 1 (AD)**
  - mutation unknown
- ❑ **PAI-1 deficiency (AR)**
  - 2bp insertion (TA) at 3' end of exon 4 resulting in a frameshift and new stop codon

# Clotting factor concentrate utilized by the Amish in Indiana



# The Community Dental Clinic





# The “Amish CDC”



# The Community Health Clinic



# What has the CHC done to date?

## □ 2009

- Established as a non-profit 501(c)(3) organization
- Collaborating with Dr. Morton in Pennsylvania & Dr. Wang in Ohio
- Wrote a Business Plan
- Formed board of directors and began meeting
- Fundraising: Community Auction
- Bought land for permanent site



**Benefit Auction**

## □ 2010

- Physician recruitment
- Private foundation grant writing
- Fundraising from private donors
- Newsletter

# What has the CHC done to date?

## □ 2011

- Physician recruitment
- Renovated temporary space in the basement of Dr. Egli's office
- Fundraising
  - 2011 Dutch Dinner
- Financial Counseling with Melvin Miller
- Initiated Genetic Survey of the community

## □ 2012

- Launched bill counseling/negotiating service
- Abstracts presented at ACMG/SIMD
- Survey Implementation
- Launched the [www.indianachc.org](http://www.indianachc.org) website

# The need for bill negotiating services



# Physician Recruitment



2012-13

- Forged relationship with University of Michigan & Parkview Health Systems**
- State Department of Health Grants**
  - NBS Follow-up
  - MCH – Genetics Medical Home
- Hired Practice Manager, Nurse Practitioner, 2<sup>nd</sup> Physician**
  - Recruiting Nurse, Dietitian, Receptionist/MA

# Plans in 2013

- Continue to prepare for the opening of the CHC**
- CHC Survey of all households to identify families needing our services**
- Fundraising**
  - 2013 Dutch Dinner
  - Apply for grant funding
  - Plan for a 2014 Community Auction
- Most importantly, open the clinic to start seeing and treating patients**
- Build an education resource room**



# Future plans beyond 2013

- Start a CHC research program**
- Expand lab services offered at the CHC**
- Implement an in-house pharmacy**
  - Will include some natural supplements & pharmacist who understands both medications and supplements and their interactions
- Build a permanent location**
- Expand to primary care**



The Community  
Health Clinic

*Preliminary results of the CHC's  
community-wide genetic survey*



# The CHC Survey

## □ Purpose of survey

- Catalogue and determine prevalence of genetic disorders
- Identify needs/allocate resources

## □ Process of the survey

- Pilot phase, revisions, full phase

Dear Community Member:

We would like to improve healthcare services for your community. As board members of the Community Health Clinic, we would like to identify any special needs that your community has related to medical conditions that can be inherited or passed on to children through genes. These conditions may cause a variety of medical problems, some of which are very serious and can be prevented if a person is diagnosed and treated early enough. Information from this survey will help us create a clinic equipped to treat these medical conditions that affect your community.

Please fill out this survey and return it in the postage-paid return envelope OR return it to your Community Health Clinic Contact Couple \_\_\_\_\_ as soon as possible. Even if no one in your household has any medical conditions that you are concerned about, you would still help us greatly by completing the survey. Please know that all your answers will remain confidential.

This survey is voluntary. Your decision whether or not to participate will not affect your ability to get quality care at The Community Health Clinic. Thank you, in advance, for your help to make The Community Health Clinic a place that serves your needs. Feel free to contact us with any questions.

**For questions about the survey:**

Rebecca Evans  
Genetic Counselor  
Indiana Hemophilia & Thrombosis Center  
Toll Free: 877-256-8837  
Direct Line: 317-871-0011 ext. 222  
Email: revans@ihctc.org

**For questions about The Community Health Clinic:**

Dennis Lehman  
President of the Board of Directors  
The Community Health Clinic  
Phone: 260-593-0108  
Mail: PO Box 9, Topeka, IN 46571

Sincerely,

**The Community Health Clinic Board of Directors**

- Dennis Lehman, President
- Lester Beechy, Vice President
- Chris Roberson, Secretary (Indiana Hemophilia & Thrombosis Center)
- Mahlon Lambright, Treasurer
- Jeffrey Brookes, MD, Director (Parkview Health)
- Wayne Brubacher, Director
- Glen Hershberger, Director
- Freeman Hostetler, Jr., Director
- Elmer Lengacher, Director
- Ernie Miller, Director
- Amy Shapiro, MD, Director (Indiana Hemophilia & Thrombosis Center)

**I. Family status**

1. Are you married?  Yes  No
2. Do you have any children?  Yes  No
  - a. If yes, how many (including deceased children)? \_\_\_\_\_

**II. Diagnosed Genetic Conditions**

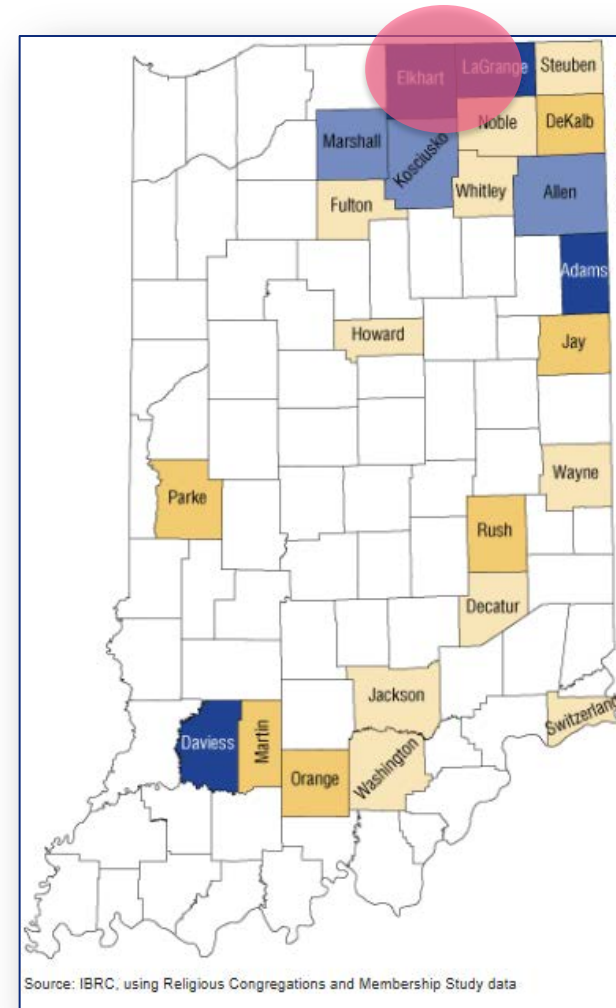
The next questions are about **diagnosed** medical conditions in your family that can be inherited or passed down to children through genes. Genes are like instructions that influence how our bodies grow, look, and work and also how we learn. Genetic conditions are caused by a change or difference in a person's genes that causes them to not work correctly. Sometimes these changes or differences are inherited or passed down from a parent, and sometimes they happen for the first time in the child. Genetic conditions usually cause a child to have special needs (slow learning or intellectual disability, seizures or convulsions, birth defects, cerebral palsy, etc.). When a baby is born with a genetic condition, signs are often present at birth or shortly after. However, some people may not show signs until later in life.

3. Have you, your husband or wife, or your living children ever been diagnosed by a doctor with any of the following:
  - a. Genetic/inherited/metabolic disorder?  Yes (List below)  No (ex. PKU, congenital adrenal hyperplasia, muscular dystrophy, etc.)
  - b. Birth defect? (ex. cleft lip or heart defect)  Yes (List below)  No
  - c. Autism and/or autism spectrum disorder?  Yes (List below)  No

Full Name	Date of Birth (MM/DD/YY)	Relationship (son, daughter, wife, etc.)	Lives in household? <input type="checkbox"/> Yes <input type="checkbox"/> No	Age at Diagnosis	Diagnosis
(example) Joe Smith	01/01/05	Son	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	1 month	PKU
			<input type="checkbox"/> Yes <input type="checkbox"/> No		
			<input type="checkbox"/> Yes <input type="checkbox"/> No		

# Progress

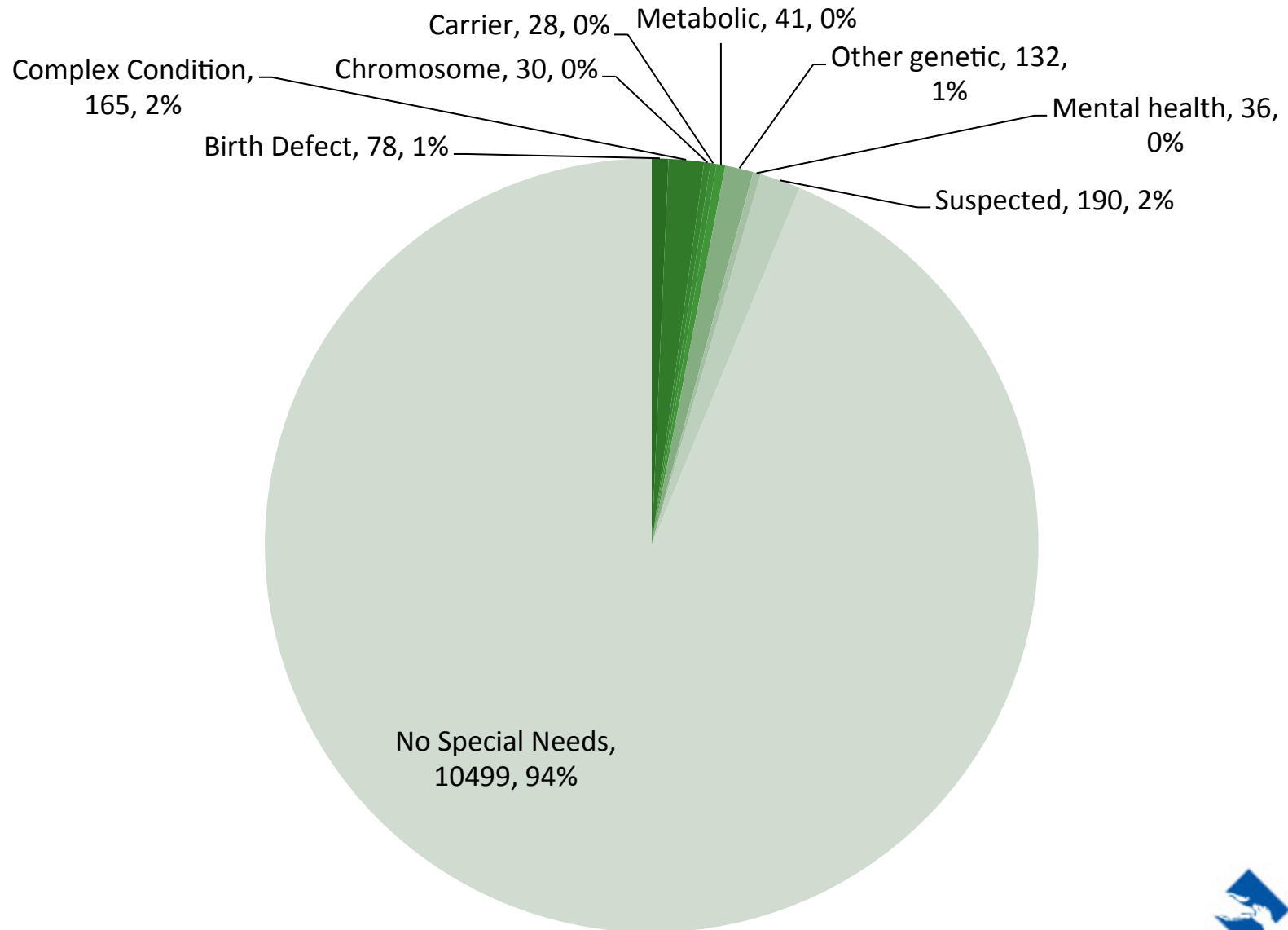
- ❑ **200 Amish church districts engaged**
  - ~5,052 households
  - ~23,744 individuals
- ❑ **141 districts returned some surveys**
  - 2,296 households
  - 11,199 individuals
- ❑ **Current response rate**
  - Households: 45%
  - Individuals: 47%

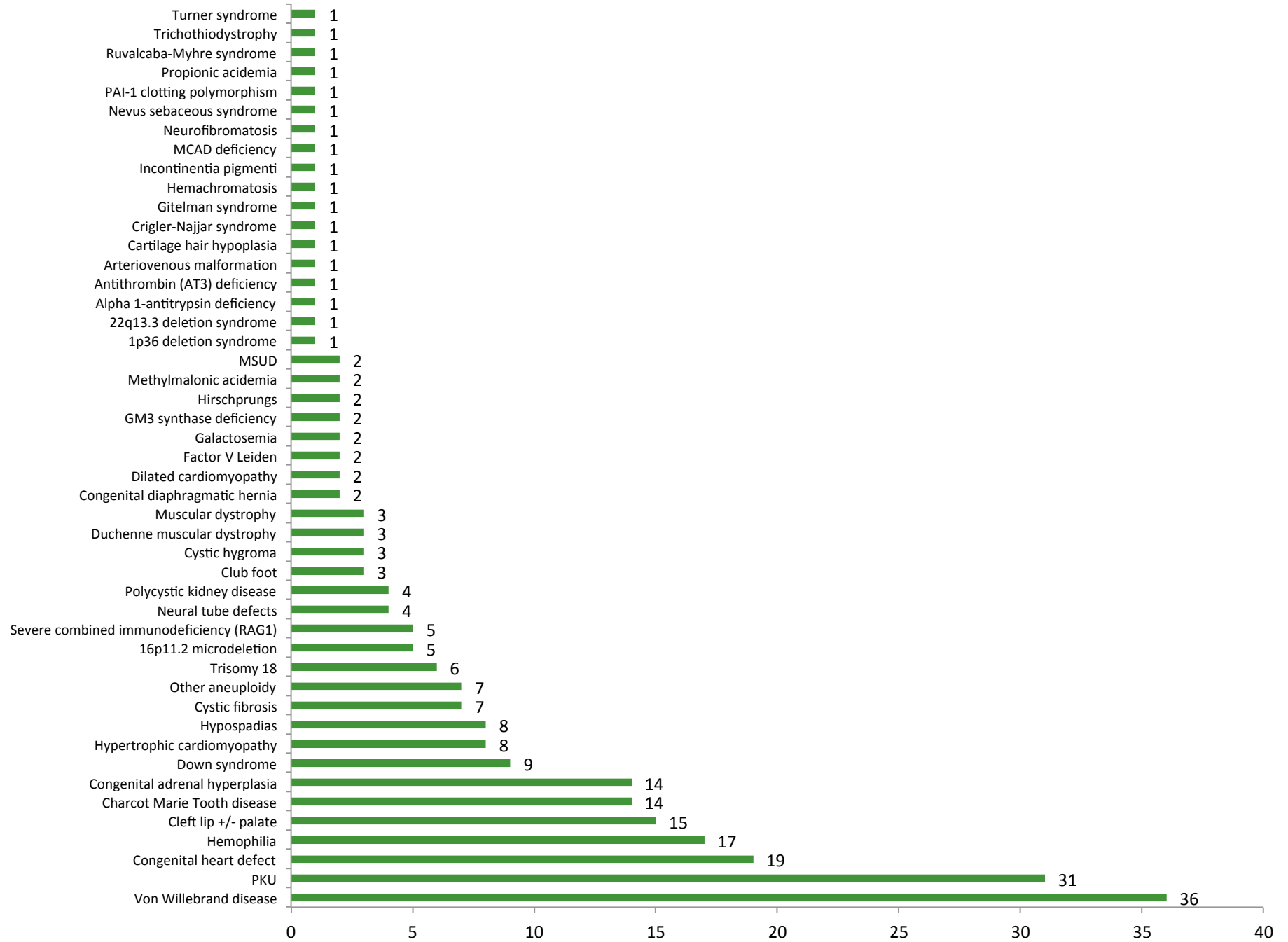


# Progress

- ❑ **209 church districts in catchment area**
  - LaGrange, Elkhart, & Nappanee area
- ❑ **62 districts engaged to date**
  - ~1,157 households
  - ~5,400 - 8,400 individuals
- ❑ **28 districts returned some surveys**
  - 272 households
  - 1,351 individuals
- ❑ **Current response rate**
  - Households: 23.5%
  - Individuals: 16-25%

# Survey Results To Date





# Other Data

