

Caregiver Survey

Multidisciplinary Clinics (MDCs)

December 2022

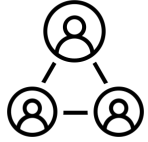
Purpose: Obtain first hand experience from individuals that attended MDCs, capture barriers for those that weren't able to, and identify ways to improve starting and maintaining MDCs.



Rare Epilepsy Network

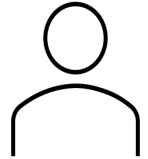
www.rareepilepsynetwork.org

Demographics of 50 Responses



Relationship to Person Dx:

- Caregivers – 31 minor child; 6 adult child; 1 unknown
- Self – 7
- Guardian – 1



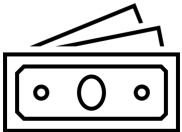
Race:

Caucasian (38); Latino of Hispanic Ancestry (4); Asian (4); African American (2); N/A (2)



Education:

Bachelor Degree (20); Masters (13) ; High School (11); PhD + (3); Trade School (1) (N/A)



Annual Household Income:

\$100-200k (13); \$200k+ (10); \$50-100k (6); \$25-50k (3); <\$25k (2); N/A (15)



Primary Language:

English (49); Spanish (1)

List of Participating Disorders

(22 + 1 DEE and 1 intractable)

8p Disorder

Angelman

Cardio-Facio Cutaneous Syndrome

CDKL5

CSNK2B

Developmental and Epileptic Encephalopathy

Dravet Syndrome

Duq15q

Glut1 Deficiency (SLC2A1)

Jeavons Syndrome

Jordan's Syndrome (PPP2R5D)

KdVS

Lennox-Gastaut Syndrome

Malan Syndrome Foundation

Phelan-McDermid Syndrome

Reflex Sympathetic Dystrophy, GM Epilepsy

Ring14

SLC6A1

Sleep-Related Hypermotor Epilepsy (SHE, NFLE, ADNFLE)

Sturge Weber (GNAQ)

STXBP1

TBC1D24

Tuberous Sclerosis Complex (TSC1 and TSC2 genes)

Uncontrollable, Intractable Epilepsy

Information on Individuals with the Diagnoses

Gender

Female (31)

Male (19)

Current Age ranged from 1 to 51;

1-17 (31)

18+ (15)

Age of diagnosis

birth to 2 year old (29) 29 were birth to 2 y/o;

18+ (3), including one at 51+

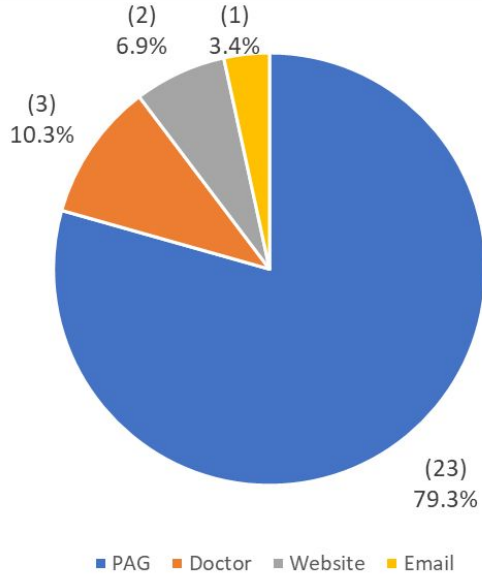
Geography

26 states represented

Majority (41) live in urban, suburbs or town centers

Awareness & Interest

Majority (79.3%) were informed through their Patient Advocacy Group (PAG).



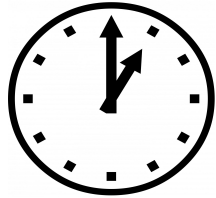
80% indicated they would attend if an MDC existed.

61% would attend even if clinic is not disease specific.



Awareness outside of PAG is limited.
Interest within caregivers is high.

Biggest Challenges

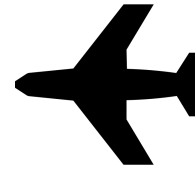


Long day/length of visits (6)
Time away (child care)
Wait to get appointment

*Visit over Multiple Days 38.5% (10)
86% seen in less than 5 months*



Scheduling/Specialist Coordination
Navigating hospital/managing in exam room



Burdens of Travel – special needs. Medically fragile (4)
Challenge of overnight EEGs

*Distance Traveled: 501+ miles 43.3% (11)
Travel by Plane 38.5% (10)*



Financial Burden

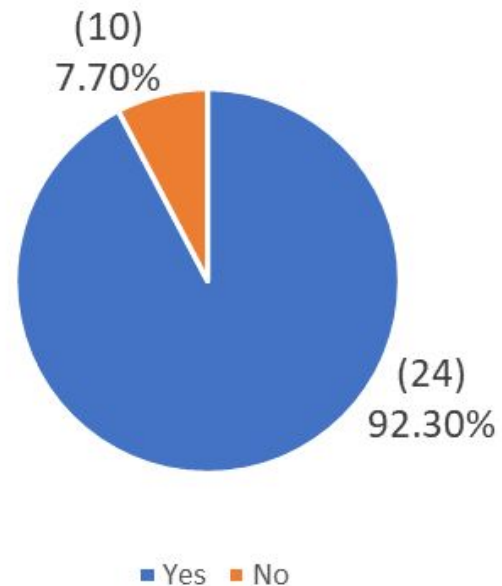
*Hotel/Air B&B 57.6% (15)
No Financial Aid 80.8% (21)*

General Visit Experience

Vast majority would return to MDC.

80.8% (21) were offered research opportunities and agreed to join!

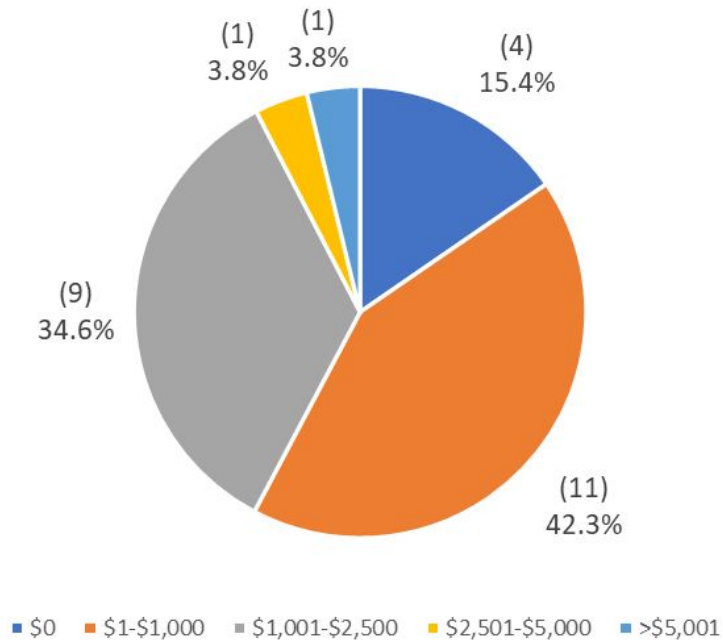
Were you able to ask questions between visits?



92.3% (24) Overall Reported Positive Experience!

Cost

Cost of Travel & Accommodations



50% had \$0 Out of Pocket Costs
No financial support was received for out of pocket costs!
(26 responders)

92 % had insurance coverage

100 % coverage 50% (13)
Deductible, Then coverage 42.3% (11)
Not covered 3.8% (1)
Partially Covered 3.8% (1)

76.9% had insurance through employer

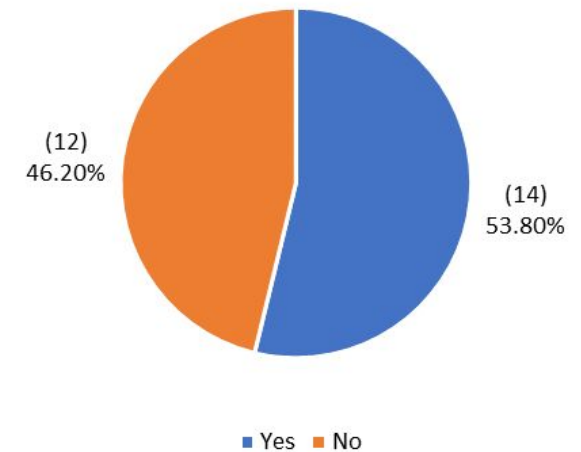


Bias: Better insurance led to majority of medical costs being covered.

Changes After Visit

- ❑ Medication changes (7) including for anxiety, behaviors, repurposed drug
- ❑ New specialists, supplements, and additional services added to the team and care – 3
- ❑ Now have a team of people to contact for comorbidities eg sleep, mobility, cognition, GI
- ❑ New, additional diagnosis eg autism
- ❑ Validated home care was doing a good job
- ❑ Device change
- ❑ New regimen for sleep
- ❑ Aging preparation
- ❑ Recommended process for implementing changes - 1 at a time; what to prioritize
- ❑ No changes

Did Home Care Change After Visit?



Most validated existing care or improved care through methodical modifications.



Benefits of MDC

- ❑ Expertise/familiarity with specific disorder
- ❑ Input from/access to collaborative multi-specialists
- ❑ One-stop reduced family stress
- ❑ Access to new specialists eg developmental peds
- ❑ Opportunity to participate in research
- ❑ Informed care and new treatment plan*
- ❑ Helpful to guide progression of disease
- ❑ Recommended interventions for behaviors, treatments, cognition that were tailored to dx
- ❑ Managing care where rural/local drs are unable/unwilling
- ❑ Time spent answering questions

“So much less stress being able to see all Dr's in one visit. Not to mention Dr's who are familiar with my child's medical condition and can collaborate if needed on my child's care.”

“We now use our clinic doctors to guide all of our child's medical care as we live in a very rural area and local physicians do not have the bandwidth to learn or understand our child's disorder.”

“Coordinated care was amazing and continued follow up and support exceptional.”

“Not only did the clinic provide excellent care and recommendations to bring back to primary caregivers, it also supports are research efforts. While not mandatory, all participants are given the opportunity to consent into a research study. And I think everyone consents.”

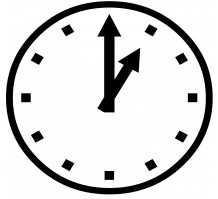
“We learned from specialists who are familiar with her rare condition. None of our preexisting medical team knew about her condition and I don't believe she was being treated correctly. The specialists at the clinic have agreed to take over continuum of care.”



96.2% (25) Would Recommend a MDC to Other Families!



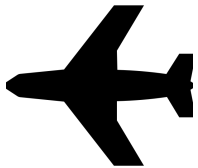
Opportunities for MDC Improvement



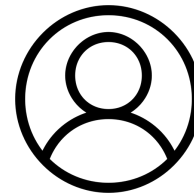
Less wait time for appointments
Less wait time between appointments on site



Day includes breaks/lunch
Better access to coordinator
Better advance planning by coordinator to assess needs in advance to focus visit



Closer to home, no travel
Less Travel Time
Single location for visits



Training for ER Doctors
Opportunities for families to meet families
Support for multiple languages
Specialists familiar with all disorders



Transparency on payments
Less Travel Time

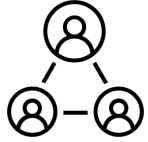


There's a need for additional clinics! Having more clinics would address most of the highlighted opportunities.

Detailed Findings

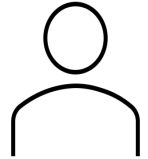
Based on Caregiver Survey Results circulated in Fall 2022

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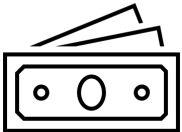
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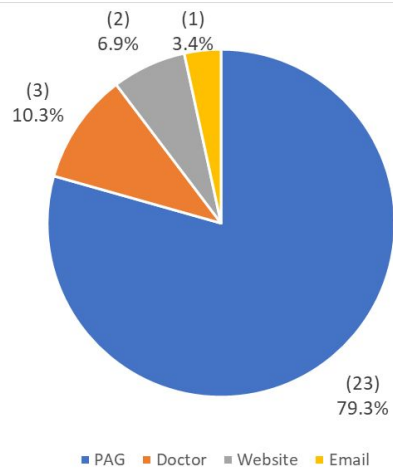
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Multidisciplinary Clinics - Awareness

Aware of Clinic

56.5% (26) = Clinic Exists
10 = Not Sure
10 = No Clinic

**Majority *79.3% or 23 people
Heard about it via the PAG!**



Will You Visit?

61.9% (26) = YES
23.8 % (10) = No Clinic
11.9% (5) = Not Sure

If a Clinic Exists, Would You Visit?

80% (16) = YES
20% (4) = No

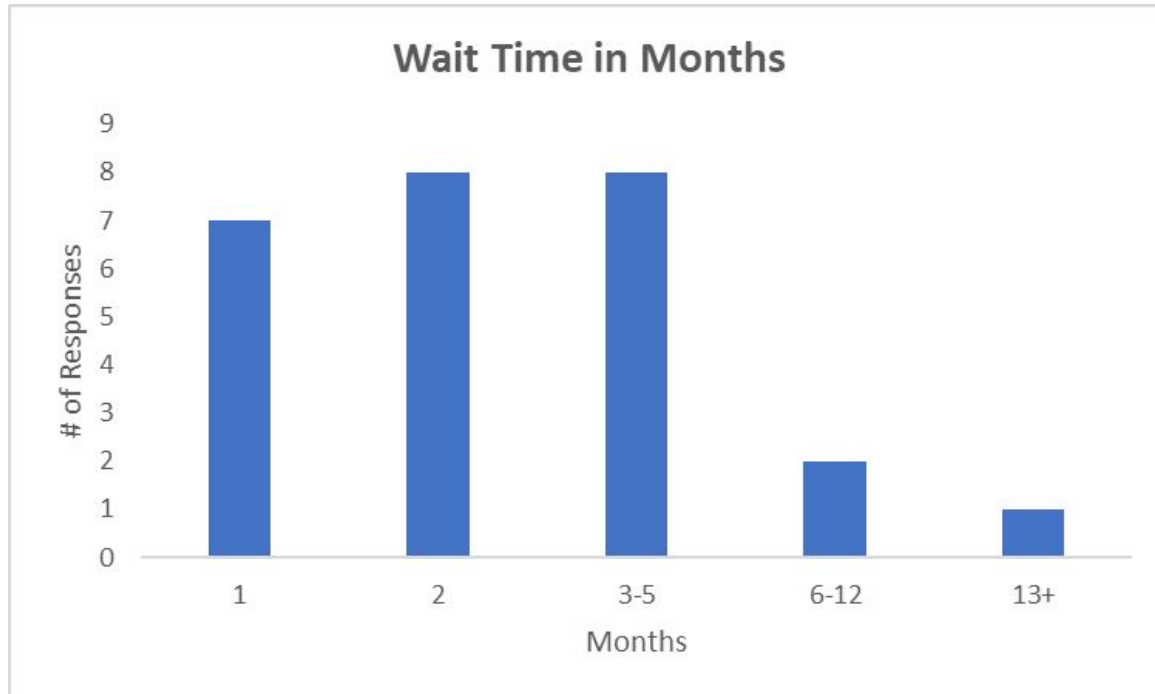
Considerations for Visiting A Clinic:

- *None exists*
- *Cost/benefits of visit*
- *Expertise of clinic*
- *Wait times to be seen*
- *Transportation*

Experience Visiting a Multidisciplinary Clinic

How Long to be Seen?

86% seen in less than 5 months



What was your Visit Length?

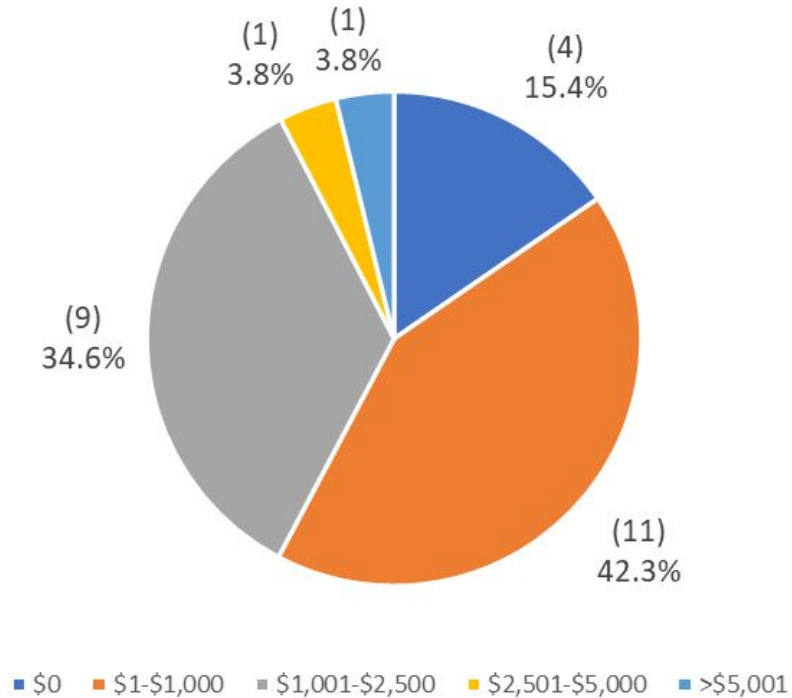
Single Day 61.5% (16)
Multiple Days 38.5% (10)

If overnight, where did you say?

Hotel/Air B&B 57.6% (15)
No Overnight 26.9% (7)
Family 7.7% (2)
Ronald McDonald 3.8% (1)
N/A 3.8% (1)

Experience Visiting a Multidisciplinary Clinic (Continued)

Cost of Travel & Accommodations



Feedback from responders....

- *Costs were just gas, parking, and/or food*
- *State waiver reimbursed gas mileage*
- *PAG Family Funds offered reimbursement*
- *Telemed so no costs*
- *Visit was part of event/sponsored hotel stay*

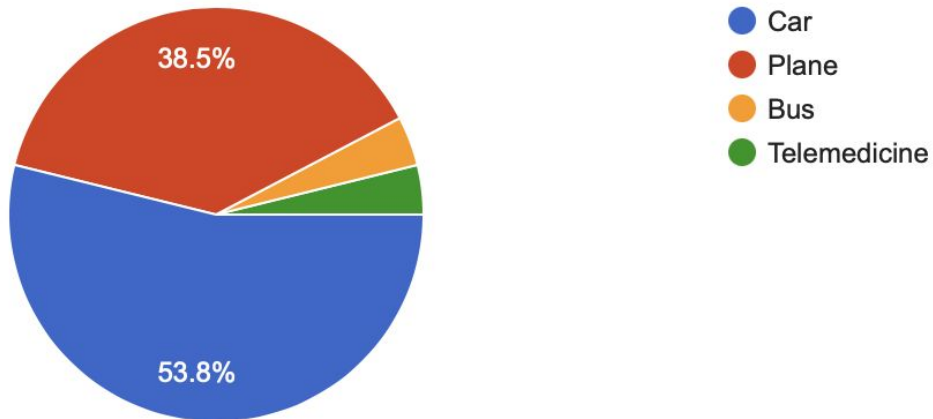
Financial Aid Available?

No 80.8% (21)
Yes 19.2% (5)

Traveling To The Clinic

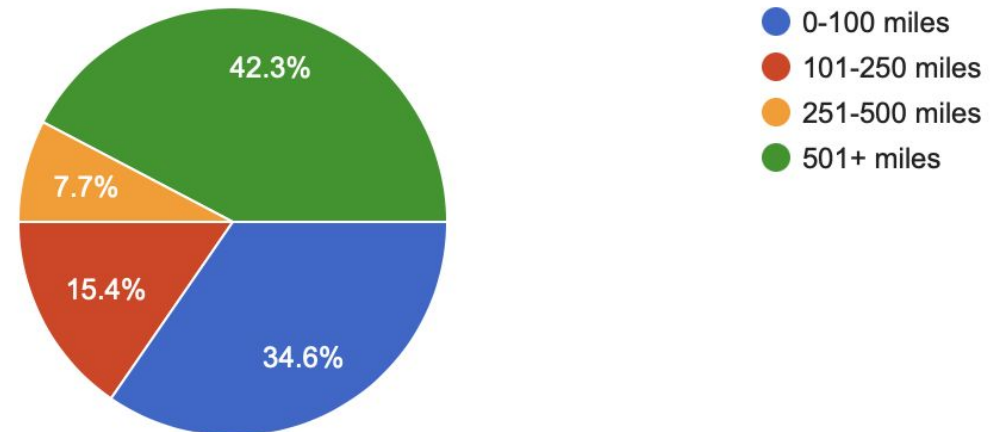
How do you travel to the Clinic?

Car 53.8% (14)
Plane 38.5% (10)



What is the distance traveled?

0-100 miles 34.6% (9)
501+ miles 43.3% (11)



Insurance

92% had coverage for visit

100 % coverage 50% (13)
Deductible, Then coverage 42.3% (11)
Not covered 3.8% (1)
Partially Covered 3.8% (1)

Insurance types (check all)

Employer 76.9% (20)
Medicaid/Medicare 53.8% (14)
Self 11.5% (3)

Preauthorization Assistance from the clinic

Yes 73.1% (19)
No 26.9% (7)

50% had \$0 Out of Pocket Costs

50% (13) = \$0
42.3% (11) = \$1-1000
7.7% (2) = \$1000-2500

No financial support was received for out of pocket costs!

(26 responders)

Comments:

- *PAG did not support medical costs;*
- *Cost for visit was deductible and similar to the cost of other doctor visits*

Clinics Visited

1. Boston Children's Hospital – CDKL5 COE, Dr. Heather Olson (1)
2. Children's Hospital Colorado – 15q - Dr. Jessica Duis (4)
3. Children's Hospital Colorado – Scott Demarest, Neurogenetics Multidisciplinary Clinic (8)
4. Children's Hospital Colorado – (1)
5. CHOP (1)
6. CHOP Engin – Dr. McDonnell (1)
7. Cincinnati Children's Hospital – Drs. Weaver & Krueger (1)
8. Cincinnati Children's – RAS Clinic (1)
9. Dallas Children's Medical Center (1)
10. Rush University – Dup15q/Angelman Clinic (1)
11. Geisinger ADM (1)
12. Kennedy Krieger (1)
13. MGH – Ron Thibert (1)
14. National Institutes of Health – Dr. Thurm (1)
15. Texas Children's – CDKL5 COE – Dr. Suter (1)

Geisinger



Texas CDKL5 Center of Excellence



Kennedy Krieger Institute

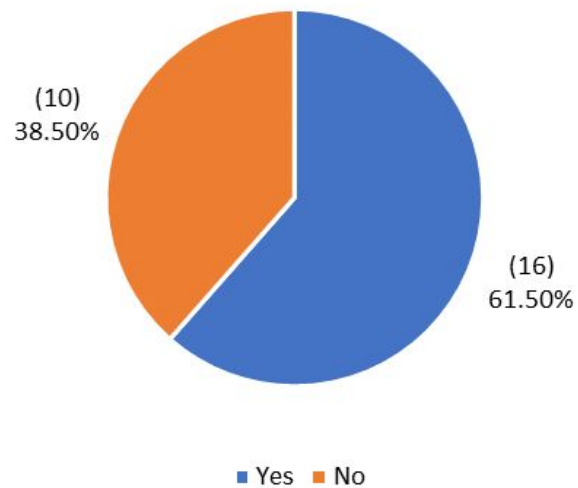


Clinics Visited, Continued

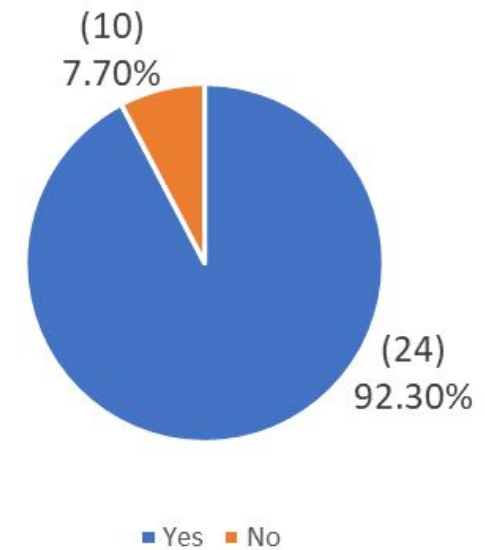
Was the clinic Focused on Specific Disorders?

80.8% (21) – Disorder Focused
7.7% (2) – Not Disorder Focused

Would you visit a general MDC Closer?



Was the Visit Helpful?



Benefits to MDC

- ❑ Expertise/familiarity with specific disorder
- ❑ Input from/access to collaborative multi-specialists
- ❑ One-stop reduced family stress
- ❑ Access to new specialists eg developmental peds
- ❑ Opportunity to participate in research
- ❑ Informed care and new treatment plan*
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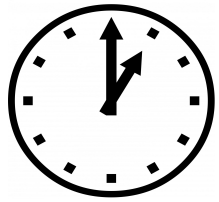
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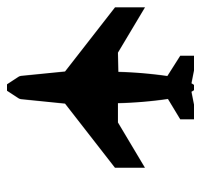
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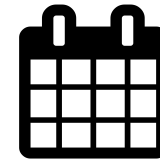
Biggest Challenges



Long day/length of visits (6)
Time away (child care)
Wait to get appointment



Burdens of Travel – special needs. Medically fragile (4)
Challenge of overnight EEGs



Scheduling/Specialist Coordination
Navigating hospital



Financial Burden

When Asked What Caregivers Would Change

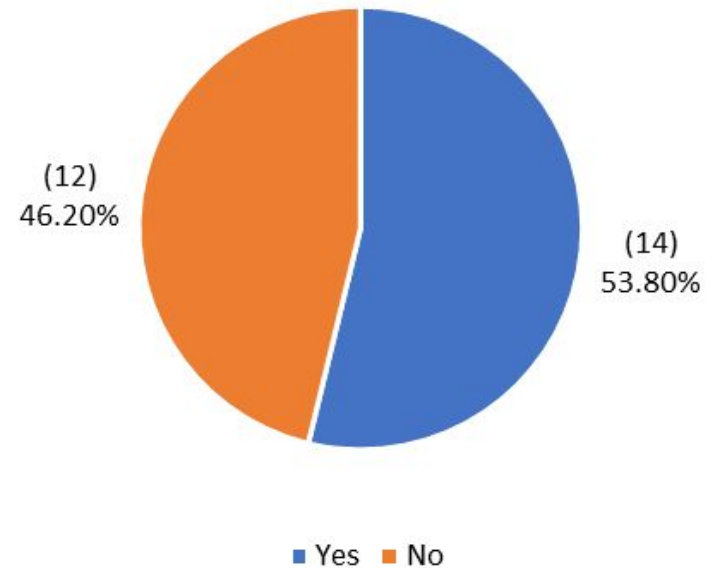
- ❑ Location; closer to home (6)
- ❑ Expand specialties into GI, Pulmonary, ENT (2)
- ❑ Meet other families (3)*
- ❑ More telehealth access
- ❑ Testing at home for interpretation by specialists
- ❑ Wait time

**Note: 57.7% (15) met other families during/after visit; 42.3% (11) did not*

Changes After Visit

- ❑ Medication changes (7) including for anxiety, behaviors, repurposed drug
- ❑ New specialists, supplements, and additional services added to the team and care – 3
- ❑ Now have a team of people to contact for comorbidities eg sleep, mobility, cognition, GI
- ❑ New, additional diagnosis eg autism
- ❑ Validated home care was doing a good job
- ❑ Device change
- ❑ New regimen for sleep
- ❑ Aging preparation
- ❑ Recommended process for implementing changes - 1 at a time; what to prioritize
- ❑ No changes

Did Home Care Change After Visit?



Connections and Follow Up

MDC connection to PCP

Did not connect with PCP 65.4% (17)
Connected with PCP 34.6% (9)

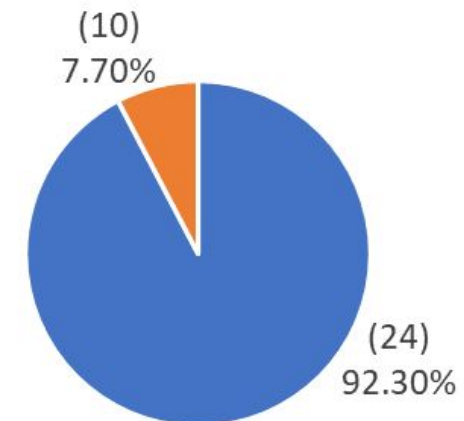
Connections were primarily via:

written summaries; clinical notes; and letters to
neurologists, pediatricians, and/or PCPs.
Also via parents as intermediaries

Did Caregiver Follow Up w/ MDC

Yes 65.4% (17)
No 34.6% (9)

Were you able to ask questions between visits?



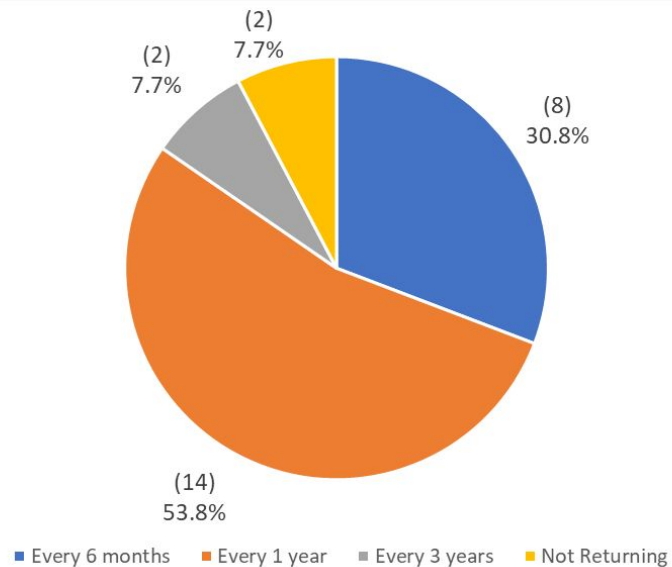
■ Yes ■ No

Future Visits and Research Opportunities

Will you return to MDC?

Yes 92.3% (24)
No 7.7% (2)

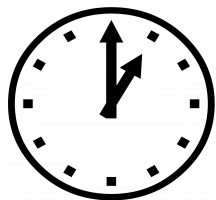
How often will you return?



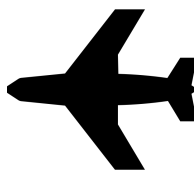
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Opportunities for MDC Improvement



Less wait time for appointments
Less wait time between appointments on site
More clinics



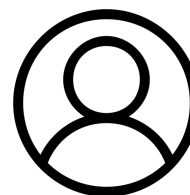
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Single location for visits



Transparency on payments
Less Travel Time



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Better advance planning by coordinator to assess needs in advance to focus visit



Training for ER Doctors
Opportunities for families to meet families
Support for multiple languages
Specialists familiar with all disorders