

Appendix 1

Impact of Batten Disease: Questionnaire for the primary caregivers of a child with Batten Disease

Participant Number _____

IMPACT OF BATTEN DISEASE:
Questionnaire for the primary caregivers of a child with Batten Disease

ABOUT YOUR CHILD

date completed: ___/___/___
mm dd yyyy

1. Child's age: _____
2. Child's age (*in years*) when first symptom was noticed: _____
3. What was the first symptom noticed? _____
4. What type of Batten Disease does your child have?
 - a. Infantile NCL
 - b. Late infantile NCL
 - c. Juvenile NCL
 - d. Variant late-infantile NCL
 - e. Other (*please specify*) _____
5. Who is *primarily responsible* for parenting the child?
 - a. mother
 - b. father
 - c. mother and father share equal responsibility
 - d. other (*please specify*): _____
 - e. _____ and _____ share equal responsibility (*please specify*)
6. Where does the child live most of the time?
 - a. At home with the primary caregiver(s)
 - b. In a nursing or assisted living facility
 - c. Other (*please describe*) _____

PRIMARY CAREGIVER(S) INFORMATION

1. Are you **male** or **female**? Please circle one.
2. What is your age? _____ years.
3. Marital status:
 - a. Married
 - b. Single
 - c. Not married but in a long-term relationship
 - d. In a legal domestic partnership
4. What is your occupation? _____
5. Total number of children: _____ children without Batten Disease and _____ children with Batten Disease.

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6. What is your relationship to your child with Batten Disease?
- a. Mother
 - b. Father
 - c. Other (step-parent, significant other of parent, a relative, etc, *please specify*): _____

PRIMARY CAREGIVER(S) INFORMATION continued

7. What is your ethnicity? (please check the one with which you *most closely* identify)
- Hispanic or Latino
 - Not Hispanic or Latino
 - Unknown
 - Not reported
8. What is your race?
- Black
 - White
 - Asian
 - Native Hawaiian or other Pacific Islander
 - American Indian or Alaska Native
 - Unknown
 - Not reported
9. *Please complete the following employment information for **all** the primary caregiver(s) of the child:*

	Father	Mother	<i>If applicable, other primary caregiver (please specify):</i> _____
Current Occupational Status	a. employed b. unemployed	a. employed b. unemployed	a. employed b. unemployed
Avg. number of hours/week that you work			
Are you currently <i>not working</i> so you have more time to care for your child with Batten Disease?	a. yes b. no	a. yes b. no	a. yes b. no
Are you currently <i>working fewer hours</i> so you have more time to care for your child with Batten Disease?	a. yes b. no	a. yes b. no	a. yes b. no

SERVICES / CARE RECEIVED FOR CHILD WITH BATTEN DISEASE

In this section, we would like to know how your child with Batten disease spends his or her day.

A. School

1. Does your child attend school? (*choose one*)
- Yes
 - No

If you answered yes, please complete the following:

2. What is the average number of hours per week your child attends school? _____ hours.

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3. What kind of classroom does your child participate in? (*choose one*)

- regular education classroom, with no pull-out services
- regular education classroom, with some pull-out services
- special education classroom, with some regular-education classes or activities
- special education classroom, self-contained (no regular-ed classes or activities)
- Other (*please describe*): _____

B. Daycare

1. Does your child attend a daycare program? (*choose one*)

- Yes No

If you answered yes, please complete the following:

2. What is the average number of hours per week your child attends daycare? _____ hours.

3. What does the daycare setting look like?

- professional daycare center
- home-based daycare (at someone else's home)
- Other (*please describe*): _____

4. How is the cost of daycare paid for? (*choose **all** that apply*)

- | | |
|---|--|
| <input type="checkbox"/> you or a family member pay out of pocket | <input type="checkbox"/> SSI or SSDI |
| <input type="checkbox"/> health insurance | <input type="checkbox"/> a state-funded program (<i>please describe</i>):
_____ |
| <input type="checkbox"/> Medicaid | <input type="checkbox"/> other (<i>please describe</i>):
_____ |
| <input type="checkbox"/> Medicaid waiver | |

5. How helpful is this service, in providing care to your child with Batten disease?

Please select only one option.

Not helpful at all
1

Slightly helpful
2

Helpful
3

Very Helpful
4

C. Other

1. Does your child attend any other **regular (daily) program** that is not a school or daycare? (*choose one*)

- Yes No

2. If yes, please describe the program: _____

3. If yes, what is the average number of hours per week your child attends? _____ hours.

4. How is the cost of this service paid for? (*choose **all** that apply*)

- | | |
|---|--|
| <input type="checkbox"/> you or a family member pay out of pocket | <input type="checkbox"/> SSI or SSDI |
| <input type="checkbox"/> health insurance | <input type="checkbox"/> a state-funded program (<i>please describe</i>):
_____ |
| <input type="checkbox"/> Medicaid | <input type="checkbox"/> other (<i>please describe</i>):
_____ |
| <input type="checkbox"/> Medicaid waiver | |

5. How helpful is this service, in providing care to your child with Batten disease?

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Please select only one option.

Not helpful at all
1

Slightly helpful
2

Helpful
3

Very Helpful
4

In this section, we would like to know what services or care your child with Batten disease receives.

A. In-home nursing care

1. Does your child currently receive in-home nursing care? (choose one)

- Yes No

If you answered yes, please complete the following:

2. What is the average number of hours per week your child receives this service? _____ hours.

3. How is the cost of this service paid for? (choose **all** that apply)

- | | |
|---|---|
| <input type="checkbox"/> you or a family member pay out of pocket | <input type="checkbox"/> SSI or SSDI |
| <input type="checkbox"/> health insurance | <input type="checkbox"/> a state-funded program (please describe):
_____ |
| <input type="checkbox"/> Medicaid | <input type="checkbox"/> other (please describe):
_____ |
| <input type="checkbox"/> Medicaid waiver | |

4. How helpful is this service, in providing care to your child with Batten disease?

Please select only one option.

Not helpful at all
1

Slightly helpful
2

Helpful
3

Very Helpful
4

B. Physical Therapy

1. Does your child currently receive physical therapy? (Physical therapy addresses mobility and general physical function, including skills such as strength, balance, or walking, choose one)

- Yes No

If you answered yes, please complete the following:

2. What is the average number of hours per week your child receives this service? _____ hours.

3. How is the cost of this service paid for? (choose **all** that apply)

- | | |
|---|---|
| <input type="checkbox"/> you or a family member pay out of pocket | <input type="checkbox"/> SSI or SSDI |
| <input type="checkbox"/> health insurance | <input type="checkbox"/> a state-funded program (please describe):
_____ |
| <input type="checkbox"/> Medicaid | <input type="checkbox"/> other (please describe):
_____ |
| <input type="checkbox"/> Medicaid waiver | |

4. How helpful is this service, in providing care to your child with Batten disease?

Please select only one option.

Not helpful at all
1

Slightly helpful
2

Helpful
3

Very Helpful
4

C. Occupational Therapy

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1. Does your child currently receive occupational therapy? (Occupational therapy addresses everyday adaptive living skills such as brushing teeth or tying shoelaces, *choose one*)

- Yes No

If you answered yes, please complete the following:

2. What is the average number of hours per week your child receives this service? _____ hours.

3. How is the cost of this service paid for? (*choose **all** that apply*)

- | | |
|---|---|
| <input type="checkbox"/> you or a family member pay out of pocket
<input type="checkbox"/> health insurance
<input type="checkbox"/> Medicaid
<input type="checkbox"/> Medicaid waiver | <input type="checkbox"/> SSI or SSDI
<input type="checkbox"/> a state-funded program (<i>please describe</i>): _____
<input type="checkbox"/> other (<i>please describe</i>): _____ |
|---|---|

4. How helpful is this service, in providing care to your child with Batten disease?

Please select only one option.

Not helpful at all
1

Slightly helpful
2

Helpful
3

Very Helpful
4

D. Other service: *please specify* _____

1. What is the average number of hours per week your child receives this service? _____ hours.

2. How is the cost of this service paid for? (*choose **all** that apply*)

- | | |
|---|---|
| <input type="checkbox"/> you or a family member pay out of pocket
<input type="checkbox"/> health insurance
<input type="checkbox"/> Medicaid
<input type="checkbox"/> Medicaid waiver | <input type="checkbox"/> SSI or SSDI
<input type="checkbox"/> a state-funded program (<i>please describe</i>): _____
<input type="checkbox"/> other (<i>please describe</i>): _____ |
|---|---|

3. How helpful is this service, in providing care to your child with Batten disease?

Please select only one option.

Not helpful at all
1

Slightly helpful
2

Helpful
3

Very Helpful
4

What services have you applied for but NOT received?

Name of service (<i>requested, not received</i>).	Reason why service was requested.	Reason service was not received.
1.		
2.		
3.		

IMPACT OF BATTEN DISEASE

In this section, we would like to know about how you, the primary caregiver, get support and information.

1. What is your current main source of information about Batten disease?
 - a. Primary care provider (general practitioner, pediatrician)
 - b. Specialist (neurologist, pediatric neurologist)
 - c. Genetic counsellor
 - d. Family member/friend
 - e. Internet website
 - f. Other: _____

2. Do you use internet websites (Batten related advocacy organizations, blog sites, clinicaltrials.gov) or social media (Facebook, web blogs) to learn about or talk about Batten disease?
 - a. Yes
 - b. No

3. If so, how often:
 - a. Daily
 - b. Weekly
 - c. Monthly
 - d. Less than once a month

4. Are you in regular contact (at least monthly) with other families caring for children with Batten Disease?
 - a. Yes
 - b. No

5. If yes, by what methods have you contacted them? Circle all that apply.
 - a. In person
 - b. Phone
 - c. Email
 - d. Website
 - e. Mail

6. Have you ever organized, or helped to organize, a fundraiser for your child and/or other children with Batten Disease?
 - a. Yes
 - b. No

7. Have you participated in any research studies, registries, or clinical trials related to Batten disease?
 - a. Yes
 - b. No

8. By which methods do you prefer to learn about Batten disease? Circle all that apply.
 - a. Health care provider
 - b. Support group
 - c. Other families who have Batten disease
 - d. Internet sites
 - e. Social media
 - f. Conferences

9. What topics would you like to hear more information about? Circle all that apply.

