

INSTRUCTIONS FOR HOSPITALS AND EMERGENCY ROOM VISITS



PUBLICATION OF BATTEN DISEASE SUPPORT & RESEARCH ASSOCIATION

HOSPITAL BOOK

The mission of BDSRA is:

To be an international support
and research networking
organization for families
of children and young
adults
with an
inherited
neurological
degenerative
disorder known
as Batten Disease.

“A light in a world of darkness...”

NOTICE TO THE READER

This Batten Disease Handbook is compiled with information from many sources concerning the topics included. Families in the organization have also contributed their specific situations that have been helpful in their own battle with Batten Disease. All material in this book is provided for information purposes only.

Although Batten Disease Support and Research Association (BDSRA) has made every reasonable effort to assure the accuracy of the information contained in this book, BDSRA is not engaged in rendering medical or other professional services and advice.

BDSRA does not guarantee or warrant that the information in the book is complete, correct, current, or applicable to every situation. BDSRA disclaims all warranties express or implied, concerning this book and the information contained herein. If medical or other expert assistance is required, the services of a competent professional should be attained.

Nancy Carney, RN
Batten Disease Support and Research

INSTRUCTION BOOK FOR HOSPITALS & EMERGENCY ROOM VISITS

Hospitals: This booklet is available for you to see the diagnosis, most recent labs, EEG, DNR issues, current medications, feedings, care issues, and what level of understanding, how much ability to communicate is present and how much is understood for this child with Batten Disease. This booklet is meant to be a reference guide, so that parents can tell you quickly about the stage of Batten Disease their child is at present and sooner emergency treatment can be initiated and not have to duplicate many tests and procedures that may have recently been done. Parents have taken much time to fill out this important information, so at this possible critical time in their child's life, treatment can begin without wasting much time. Thank You! If questions, you may contact the following:

Batten Disease Support and Research Association
166 Humphries Drive
Reynoldsburg, OH 43068
1-800-448-4570
www.bdsra.org
Lance Johnston, Executive Director
Nancy Carney RN, Medical Liaison/Educator
1-877-642-5512

THE _____ FAMILY

FAMILY PHOTO HERE

Who is in this picture?

HOME ADDRESS

Telephone: _____

CHILD PHOTO HERE

Child's Name: _____

Date of Birth: _____

Diagnosis: _____

EMERGENCY NUMBERS

PARENT'S PAGER/S _____
PARENT'S CELL PHONE/S _____

EMERGENCY CONTACTS IF PARENT CANNOT BE REACHED

1. _____

Telephone _____ Cell _____

2. _____

Telephone _____ Cell _____

PHYSICIAN _____

Telephone _____ Answering service _____

PHYSICIAN _____

Telephone _____ Answering service: _____

PHARMACY _____

Telephone _____

INSURANCE COMPANY _____

Telephone _____

Copy of Insurance Card

EMPLOYER _____

Telephone _____

PREFERRED HOSPITAL _____

Telephone _____

RESPIRATORY THERAPIST _____

Telephone: _____ Cell: _____

HOME HEALTH NURSE: _____

Telephone: _____ Cell: _____

EMERGENCY INFORMATION

Is there a copy of the diagnosis of Batten Disease? Yes _____ No _____

If no, can a copy be obtained for this book? _____

Is there a signed letter authorizing treatment in case of emergency? _____

Is it included with this information book? _____

If not, where is it? _____

Is a copy on file with the hospital and/or physician? _____

If yes, which hospital and/or physician? _____

Is there a DNR (do not resuscitate) letter in place? _____
Is it included with this information book? _____
If not, where is it? _____
Is a copy of the DNR on file with the hospital and/or physician? _____
If yes, which hospital and/or physician? _____
Has there been a recent EEG done or any lab work/drug levels? If so, is there a copy attached, and if not can a copy be obtained for the hospital? _____
Other emergency information/instructions: _____

MEDICATIONS

PLEASE UPDATE AS DOSAGES AND MEDICATIONS CHANGE

Medication allergies _____
Date updated: _____
1. Medication: _____
Dosage: _____
Time/s given: _____
How given: (oral/Gtube/etc.) _____
Prescribing physician: _____
Possible severe side effects: _____
2. Medication: _____
Dosage: _____
Time/s given: _____
How given: (oral/Gtube/etc.): _____
Prescribing physician: _____
Possible severe side effects: _____
3. Medication: _____
Dosage: _____
Time/s given: _____
How given (oral/Gtube/etc.): _____
Prescribing physician: _____
Possible severe side effects: _____
4. Medication: _____
Dosage: _____
Time/s given: _____
How given: (oral/Gtube/etc.): _____
Prescribing physician: _____
Possible severe side effects: _____
5. Medication: _____
Dosage: _____
Time/s given: _____
How given (oral/Gtube/etc.): _____
Prescribing physician: _____
Possible severe side effects: _____
6. Vitamins/supplements: _____
Dosage: _____
Time/s given: _____
Additional instructions/information: _____

RESPIRATORY

Does your child have apnea or other respiratory/breathing difficulties? _____
Explain: _____

Does your child need suctioning? _____
Specific instructions regarding suctioning: _____

Does your child receive breathing treatments? ____ If yes, when: _____
Specific instructions regarding breathing treatments: _____

In the event your child stops breathing, your instructions are: (i.e. call 911, do CPR, keep comfortable) _____

Any additional information/instructions? _____

SEIZURES

Does your child have seizures? _____
If so, describe in detail: _____

How long do the seizures generally last? _____
What are your instructions in the event your child has a seizure? _____

Under what circumstances do you want the paramedics to be called? (i.e. – after 3 minutes or 5 minutes of a seizure) _____

Seizures must be recorded by careprovider! Where? _____
What usually happens during a seizure? _____

What usually happens after a seizure? (Does your child sleep, etc?) _____

In the event of a second seizure or multiple seizures, your instructions are: _____

Additional information/instructions: _____

COMMUNICATION

Is your child verbal? Yes_____ No_____

If your child is not verbal, how does he/she communicate? _____

Do you have/use alternative communicative devices? _____

Brief description of how it works: _____

How does your child ask to be picked up or held? _____

How does your child express an interest in playing a game or with a favorite toy or listening to a favorite video or music? _____

Does your child use sign language or a communicator? Yes____ No_____

If yes, please explain how this is done. _____

If necessary attach pictures someplace in this book.

How does your child communicate an interest in a particular activity? _____

How does your child communicate the following?

Hungry _____ Thirsty _____

Tired _____ Happy _____

Hot _____ Cold _____

Brother _____ Sister _____

Mom _____ Dad _____

Blanket _____ Bath _____

Toilet _____ Diaper _____

Bed _____ Dog _____

Cat _____ Pain _____

TV _____ Music _____

Hi _____ Bye _____

Car _____ Walk _____

Outside _____ Inside _____

Sad _____

Angry _____

Play with me _____

Leave me alone _____

I want more _____

I'm finished _____

Please _____

Thank you _____

I'm sick _____

Other _____

Is there any additional information that would help the doctor or nursing care giver better understand your child's communication? _____

BEHAVIOR

What is the child's normal temperament? _____

What makes your child happy? _____

Does your child have outbursts, i.e. hitting, anger, belligerence, biting, screaming, yelling, etc.?

If yes, explain: _____

What do you do? _____

Favorite games/toys? _____

Does your child run or wander away? _____

Do you have a specific behavior plan? Explain. _____

DIET

Does your child eat by mouth? _____

IF YES.....

What foods does your child like? _____

What foods does your child dislike? _____

Does your child have any food allergies? (explain)

Does your child swallow well? _____

Chew well? _____

Does food need to be prepared a special way? _____

Does your child need assistance eating? _____

If yes, how? _____

Is there a specific position or any adaptive equipment to be used to help your child eat? _____

Where are your child's food, utensils, and adaptive equipment? _____

Are there any problems with drinking? (if yes, explain) _____

Does your child use adaptive device/s for drinking? _____

Is your child fed bolus or by feeding pump? _____

Name of formula/equipment? _____

How much formula and what times? _____

Any special instructions regarding preparation of formula? _____

Do you check for residuals? _____

How much residual is normal? _____

How much water is given after feeding and medications? _____

What is to be done in case of a clogged tube or equipment malfunction? _____

How much water is in the balloon if your child has a foley tube for his/her tube? _____

How often do you change the feeding tube? _____

What size is the feeding tube? _____

Do you have a spare feeding tube? _____

Any additional information/instructions? _____

URINARY

How much water is in the balloon if the child has a foley catheter? _____

If your child has a foley catheter, when was it last changed? _____

How much urinary output is normal in a 24 hr. period? _____

How often does your child urinate? _____

Do you straight cath your child? _____

Any additional information/instructions? _____

ADAPTIVE EQUIPMENT

Does your child use adaptive equipment? Yes _____ No _____

What kind of adaptive equipment is used? _____

When is equipment to be used? _____

Additional information: _____

BED AND NAP TIME

When is your child's bedtime? _____

Nap time? _____

Does your child sleep alone? _____

Is your child afraid of the dark? _____

Does a light need to be left on? _____

Is there a special toy, blanket music or other thing that your child likes to sleep with? _____

Are there special positioning requirements when laying down? _____

Does your child need to be turned? If yes, how often? _____

Do you observe any special nap or bedtime routines? _____

Does your child usually sleep through the night? _____

How long does your child normally nap? _____

Additional information/instructions _____

PERSONAL HYGIENE

Does your child use the toilet? _____

Alone? _____

If not, what assistance is needed? _____

Does your child use diapers? _____

Training pants? _____

Potty chair? _____

Can your child brush his/her own teeth? _____

Need assistance? _____

How? _____

Where is his/her toothbrush and paste? _____

If unable to clean own teeth, is there special oral hygiene that needs to be done? _____

Explain: _____

Can your child dress him/her self? _____

What assistance may be necessary? _____

Can your child bathe his/herself? _____

What is bathing schedule? _____

Is there adaptive equipment to be used for bathing? (explain) _____

Any additional information that has not been covered? _____

SCHEDULE

Describe your child's expected daily routine, including medications and meals/feedings:

7:00 A.M. _____

8:00 A.M. _____

9:00 A.M. _____

10:00 A.M. _____

11:00 A.M. _____

12:00 P.M. _____

1:00 P.M. _____

2:00 P.M. _____

3:00 P.M. _____

4:00 P.M. _____

5:00 P.M. _____

6:00 P.M. _____

7:00 P.M. _____

8:00 P.M. _____

9:00 P.M. _____

10:00 P.M. _____

11:00 P.M. _____

12:00 A.M. _____

1:00 A.M. _____

2:00 A.M. _____

3:00 A.M. _____

4:00 A.M. _____

5:00 A.M. _____

6:00 A.M. _____