**SURVEY for patients suffering from Canavan Disease**

Date when this questionnaire was completed / / 

day month year

Name of person completing this form: ___________________________

Possibility of contact (e-mail/ phone): _____________________________

Dear Family,

Please fill out this form to the best of your knowledge and send it back to us within 2 weeks. Leave out answers that you are not sure about. You can always contact us for support:

Dr. Annette Bley  
University Hospital Eppendorf  
Pediatric Neurology  
Hamburg, Germany  
Phone 0049-40-74105-6391  
Email: abley@uke.de

We also may contact you to clarify some of the answers.
Family history

In which country/city does your child live (country of origin)? ___________________________

Are the biologic parents related to each other by blood?  □ yes □ no □ unknown

Does the child have relatives that are / have been affected by the same disease?  □ yes □ no

If other family members are affected:
  How many siblings are affected? _______
  How many siblings are unaffected? _______
  How many other relatives are affected? _______

If your child has other relatives that are affected by the same disease, how are they related to your child? ___________________________________________________
  (i.e. maternal uncle of the child)

What are the ethnic backgrounds of the biologic parents? (Hispanic or non hispanic)
  Mother ___________________________  Father ___________________________

What is the race of the biological parents?
  Mother ___________________________  Father ___________________________

Pregnancy and Perinatal history

Did the mother of the child take any drugs during pregnancy? □ yes □ no □ unknown

Was delivery at full term (after 38th week of pregnancy)?  □ yes □ no

If not, at what gestational age was your child born? _____ weeks

Birth weight _______ lbs / grams

Length at birth _______ inches / cm

APGAR score ___ / ___ / ___ (1 min / 5 min / 10 min)

Was the baby healthy after birth?  □ yes □ no □ unknown

If the baby was not healthy after birth, problems in the neonatal period were due to:
  (please check all that apply)
  □ Respiratory distress  □ Metabolic abnormalities
  □ Apnea (did not breath)  □ Neurological abnormalities
  □ Stridor (high-pitched wheezing sound)  □ Head ultrasound abnormalities
  □ Feeding problems  □ Malformation of body parts
  □ Icterus (jaundice)  □ Nystagmus (uncontrolled eye movements)
  □ Infections  □ Arthrogryposis (congenital stiffness of joints)
  □ Other (please specify: ______________________)

How long did the newborn stay in hospital? _____ days
First symptoms and diagnosis of Canavan Disease

The infant was completely normal before the onset of the first symptoms of the disease.

☐ yes  ☐ no

What were the symptoms at the onset of the disease? (please check all that apply)

- Developmental delay
- Low muscle tone ('floppiness')
- Feeding problems (poor sucking)
- Failure to thrive (poor weight gain or growth)
- Abnormal eye movements
- Poor vision
- Irritability
- Macrocephaly (head too large)
- Poor head control
- Other (please specify)

First symptoms occurred at the age of _____ year(s) and _____ month(s)

The diagnosis was confirmed at the age of _____ year(s) and _____ month(s)

How was the diagnosis confirmed? (please check all that apply)

- NAA (N-acetylaspartate) elevated in urine
- NAA elevated by MRS
- ASPA (aspartoacylase) activity decreased in skin cells
- ASPA activity decreased in blood cells
- Mutations in ASPA gene
- Other (please specify)

In case mutations in ASPA gene were found, please specify the mutations:

_________________________________________________________________

Was cerebrospinal fluid (CSF) protein elevated?  ☐ yes  ☐ no

Are biological samples available (blood, cerebrospinal fluid, urine, tissue)?

☐ yes  ☐ no

If biological samples are available, whom can we contact?

_________________________________________________________________

(Address of physician, hospital, medical center, or laboratory)
Psychomotor development

Eyesight and hearing
Was your child ever able to follow an object visually?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did you notice a decline of visual abilities in your child?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did you notice a total loss of visual function in your child?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no

Was your child able to hear?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did you notice a decline of hearing in your child?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did you notice a complete loss of hearing in your child?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no

Did you notice a hypersensitivity to noise (startling) in your child?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, was the hypersensitivity to noise lost?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no

Motor skills
Did your child gain head control?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did your child lose head control?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no

Was your child able to roll over from back to front or front to back?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did your child lose the ability to roll over?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no

Was your child able to sit without support?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did your child lose the ability to sit without support?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no

Was your child able to sit with support?
☐ yes, at the age of ____ year(s) ____ month(s)  ☐ no
If yes, did your child **lose the ability to sit with support**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child learn to **crawl** independently?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child **lose the ability to crawl** independently?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child learn to **stand up** without support?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child **lose the ability to stand up** independently?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child learn to **walk with support**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child **lose the ability to walk without support**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child learn to **walk without support**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child **lose the ability to walk with support**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

**Fine motor skills**

Did your child learn to **reach for an object**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child lose the ability to reach for an object?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child **gain any voluntary hand function** (e.g. hold cup)?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child lose hand function completely?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child learn to **transfer an object from hand-to-hand**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child lose the ability to transfer an object from hand-to-hand?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did your child learn to **scrawl / draw**?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

If yes, did your child lose the ability to scrawl / draw?

☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
Development of language and other skills

Was your child able to imitate noises?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did your child lose the ability to imitate noises?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Was your child able to communicate with you?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did your child lose the ability to communicate?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Was your child able to speak single words (i.e. mama, dada)?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, how many words was the child able to speak? ______ word(s)
If yes, did your child lose the ability to speak words?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Was your child able to speak single sentences?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did your child lose the ability to speak single sentences?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Was your child able to count to five?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did your child lose the ability to count to five?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Did the child understand language?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did your child lose the ability to understand language?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Was your child able to tell stories?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did your child lose the ability to tell stories?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no

Was your child able to read?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
If yes, did the child lose the ability to read?
☐ yes, at the age of ____ year(s) ____ month(s) ☐ no
Was your child able to write?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

If yes, did your child lose the ability to write?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

Was your child able to eat by himself / herself?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

If yes, did your child lose the ability to eat by himself / herself?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

Was your child toilet trained?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

If yes, did your child lose toilet training skills?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

Neurological findings

Was spasticity diagnosed (increased muscle tone or stiffness)?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

Did seizures (epileptic fits) occur?

☐ yes, at first at the age of ____ year(s) ____ month(s)   ☐ no

Did abnormal eye movements (nystagmus) occur?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

Were irregularities of the optic nerve or retina diagnosed?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

If yes, please specify: ______________________________________

Did involuntary (abnormal hyperactive) movements of the body occur?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

Were muscle reflexes (deep tendon reflexes) reduced or have other signs of impaired peripheral nerves (i.e. reduced sensitivity to touch, pain or vibration) been diagnosed?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

If yes, please specify which: __________________________________________________

Did you notice any impairment of cognitive function (i.e. poor concentration, forgetfulness, learning disability) in your child?

☐ yes, at the age of ____ year(s) ____ month(s)   ☐ no

If yes, please specify which: __________________________________________________
Did your child suffer from **mood disorders** (i.e. depression, anxiety etc.)?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

If yes, please specify which: __________________________________________________

### Other health problems

Did frequent **vomiting** occur?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Did your child suffer from **constipation**?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Did your child suffer from **gastro-oesophageal reflux**?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Was **surgery for prevention of gastric reflux** performed?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Did your child need **gastric tube feeding**?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Did your child have **problems with excessive secretions / mucus**?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Did your child have **other problems with breathing**?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

Did any **renal problems** occur?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

If yes, which renal problems occurred?  _______________________________________

Did your child have **other health problems** that have not been mentioned yet?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

If other health problems occurred, please specify which:

_________________________________________________________________________

_________________________________________________________________________

Did your child receive **physical therapy or other supportive therapy**?

- [ ] yes, at the age of ___ year(s) ___ month(s)  
- [ ] no

If yes, what **other types of training or support** did your child get?  (please specify)

_________________________________________________________________________

_________________________________________________________________________
Which **type of school** (Kindergarten / regular school / special school) did your child visit?

Type of school: ______________ from the age of ______ to ______ years

Type of school: ______________ from the age of ______ to ______ years

How was the **evolution of the disease**? (please check all that apply)

☐ stable, from the age of _____ to _____ month(s) / (year(s)

☐ intermittent, from the age of _____ to _____ month(s) / (year(s)

☐ slowly progressive, from the age of _____ to _____ month(s) / (year(s)

☐ quickly progressive, from the age of _____ to _____ month(s) / (year(s)

☐ none of the above, from the age of _____ to _____ month(s) / (year(s)

**Diagnostic workup**

*You may have reports of the test results. If you have them, please attach a copy of the results. Explanations of some procedures can be found in the attached information form.*

Was an (MRI) of the head done?  
☐ yes  ☐ no

If yes, who can we contact for pictures or reports?

________________________________________________________

(Address of physician, hospital or medical center)

Were **nerve conduction studies** performed?  
☐ yes  ☐ no

If yes, was nerve conduction impaired?  
☐ yes  ☐ no

Was a hearing test performed (auditory brainstem response, BEARs)?  
☐ yes  ☐ no

If yes, the results were abnormal?  
☐ yes  ☐ no

Were **visual evoked potentials (VEPs)** tested?  
☐ yes  ☐ no

If yes, the results were abnormal?  
☐ yes  ☐ no

Was an **electroretinogram (ERG)** performed?  
☐ yes  ☐ no

If yes, the results were abnormal?  
☐ yes  ☐ no

Were **motor evoked potentials (MEPs)** tested?  
☐ yes  ☐ no

If yes, the results were abnormal?  
☐ yes  ☐ no

Were **sensory evoked potentials (SEPs)** tested?  
☐ yes  ☐ no

If yes, the results were abnormal?  
☐ yes  ☐ no

Was an **electroencephalogram (EEG)** performed?  
☐ yes  ☐ no

If yes, the results were abnormal?  
☐ yes  ☐ no
Was **head circumference** measured?  
☐ yes  ☐ no

If head circumference was measured, which value was noted?

- _______ inches / cm  at the age of _____ year(s) and _____ month(s)
- _______ inches / cm  at the age of _____ year(s) and _____ month(s)
- _______ inches / cm  at the age of _____ year(s) and _____ month(s)
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- _______ inches / cm  at the age of _____ year(s) and _____ month(s)
- _______ inches / cm  at the age of _____ year(s) and _____ month(s)

### Development of seizures, language skills and visual abilities across age

<table>
<thead>
<tr>
<th>Age</th>
<th>How often did seizures occur?</th>
<th>How were the language skills?</th>
<th>How were the visual abilities of your child?</th>
</tr>
</thead>
</table>
| 1st year | ☐ no seizures  
☐ 1-2 seizures / year  
☐ less than 12 seizures / year  
☐ more than 12 seizures / year | ☐ normal for age  
☐ minor difficulties  
☐ major difficulties  
☐ no verbal contact | ☐ normal  
☐ diminished, good spatial orientation  
☐ poor, spatial orientation difficult  
☐ no visual ability |
| 2nd year | ☐ no seizures  
☐ 1-2 seizures / year  
☐ less than 12 seizures / year  
☐ more than 12 seizures / year | ☐ normal for age  
☐ minor difficulties  
☐ major difficulties  
☐ no verbal contact | ☐ normal  
☐ diminished, good spatial orientation  
☐ poor, spatial orientation difficult  
☐ no visual ability |
| 3rd year | ☐ no seizures  
☐ 1-2 seizures / year  
☐ less than 12 seizures / year  
☐ more than 12 seizures / year | ☐ normal for age  
☐ minor difficulties  
☐ major difficulties  
☐ no verbal contact | ☐ normal  
☐ diminished, good spatial orientation  
☐ poor, spatial orientation difficult  
☐ no visual ability |
| 4th year | ☐ no seizures  
☐ 1-2 seizures / year  
☐ less than 12 seizures / year  
☐ more than 12 seizures / year | ☐ normal for age  
☐ minor difficulties  
☐ major difficulties  
☐ no verbal contact | ☐ normal  
☐ diminished, good spatial orientation  
☐ poor, spatial orientation difficult  
☐ no visual ability |
| 5th year | ☐ no seizures  
☐ 1-2 seizures / year  
☐ less than 12 seizures / year  
☐ more than 12 seizures / year | ☐ normal for age  
☐ minor difficulties  
☐ major difficulties  
☐ no verbal contact | ☐ normal  
☐ diminished, good spatial orientation  
☐ poor, spatial orientation difficult  
☐ no visual ability |
| 6th year | ☐ no seizures  
☐ 1-2 seizures / year  
☐ less than 12 seizures / year  
☐ more than 12 seizures / year | ☐ normal for age  
☐ minor difficulties  
☐ major difficulties  
☐ no verbal contact | ☐ normal  
☐ diminished, good spatial orientation  
☐ poor, spatial orientation difficult  
☐ no visual ability |
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<th>How were the visual abilities of your child?</th>
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</thead>
<tbody>
<tr>
<td>7th year</td>
<td>□ no seizures</td>
<td>□ normal for age</td>
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<td>□ minor difficulties</td>
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<td>□ more than 12 seizures / year</td>
<td>□ no verbal contact</td>
<td>□ no visual ability</td>
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<td>8th year</td>
<td>□ no seizures</td>
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<td>□ normal</td>
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<td>□ minor difficulties</td>
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<td>□ no verbal contact</td>
<td>□ no visual ability</td>
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<td>9th year</td>
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<td>□ normal for age</td>
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<td>□ no visual ability</td>
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<td>10th year</td>
<td>□ no seizures</td>
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<td>11th year</td>
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<td>13th year</td>
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<td>14th year</td>
<td>□ no seizures</td>
<td>□ normal for age</td>
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<td>15th year</td>
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### Experimental therapies

Did your child undergo any experimental treatment?  
☐ yes  ☐ no

If yes, which experimental treatment? (i.e. bone marrow transplantation, stem cell transplantation, medications or others)

Please specify which: ________________________________________________

Which positive effect(s) of the experimental treatment did occur? (please specify)

________________________________________________________________________

________________________________________________________________________

Which negative effect(s) of the experimental treatment did occur? (please specify)

________________________________________________________________________

________________________________________________________________________

Did your child ever receive any medication that was thought to ameliorate the course of the disease?  
(i.e. Glycerol triacetate (GTA), Lithium Citrate (Eskalith), Acetazolamide (Diamox) etc.)

☐ yes  ☐ no

If yes, please specify which one(s): ________________________________________________

Did your child ever take any nutritional supplements that were thought to ameliorate the course of the disease?  
(i.e. Coenzyme Q10, Alpha-Lipoic Acid, Acetyl -L-Carnitine etc.)

☐ yes  ☐ no

If yes, please specify which one(s): ________________________________________________

<table>
<thead>
<tr>
<th>Age</th>
<th>How often did seizures occur?</th>
<th>How were the language skills?</th>
<th>How were the visual abilities of your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐ no seizures</td>
<td>☐ normal for age</td>
<td>☐ normal</td>
</tr>
<tr>
<td></td>
<td>☐ 1-2 seizures / year</td>
<td>☐ minor difficulties</td>
<td>☐ diminished, good spatial orientation</td>
</tr>
<tr>
<td>16th year</td>
<td>☐ less than 12 seizures / year</td>
<td>☐ major difficulties</td>
<td>☐ poor, spatial orientation difficult</td>
</tr>
<tr>
<td></td>
<td>☐ more than 12 seizures / year</td>
<td>☐ no verbal contact</td>
<td>☐ no visual ability</td>
</tr>
<tr>
<td></td>
<td>☐ no seizures</td>
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<td>☐ normal</td>
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<td>☐ no verbal contact</td>
<td>☐ no visual ability</td>
</tr>
</tbody>
</table>
Which of the medication had a benefit to your child?
_____________________________________________________________________________
_____________________________________________________________________________

Which benefit did it show? ______________________________________________________

______________________________________________________________________________

Which negative side effect did it have? _____________________________________________

______________________________________________________________________________

Which of the experimental medications showed only negative side effects?
______________________________________________________________________________

Which side effects did it show?
______________________________________________________________________________
______________________________________________________________________________

Did your child take medication for spasticity?
☐ yes  ☐ no
If yes, please specify which: ____________________________________________________
If medication for spasticity was given, when first and until when was it given?
From _____ year(s) _____ month(s) until _____ year(s)_____ month(s)

Was medication for seizures given?
☐ yes  ☐ no
If yes, please specify which: ____________________________________________________
If medication for seizures was given, when first and until when was it given?
From _____ year(s) _____ month(s) until _____ year(s)_____ month(s)

Did your child take medication for dystonia (movement disorders)?
☐ yes  ☐ no
If yes, please specify which: ____________________________________________________
If medication for seizures was given, when first and until when was it given?
From _____ year(s) _____ month(s) until _____ year(s)_____ month(s)
What **other drugs** did your child take for prolonged periods of time?

(if possible please note also the duration of administration of this medication)

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

You may attach any comments that you consider to be important.

**Thank you for your support!**

**You are helping other families.**